Changing family portraits: Sudden existential absence during delirium

A phenomenological study of the lived experience of family members during their older person’s delirium

Jennifer Lynn Day

AssocDipComHlthNurs (OccHlthNurs), BHSc (Nurs), MEd (AdultEd)

Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy (Nursing), School of Nursing and Midwifery, The University of Newcastle, Australia.

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STATEMENT OF ORIGINALITY

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository, subject to the provisions of the Copyright Act 1968.

Jennifer Lynn Day

9th December 2013
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Completing a doctoral thesis is an exciting path to take. It is rewarding as well as challenging and, when undertaken part time, somewhat lengthy. My success in travelling this path is not mine alone. It reflects the support others have graciously offered along the way, support I would like to acknowledge here in my thesis.

During the study I was privileged to meet and receive the generous support and commitment of fourteen family members. Without their trust and willingness to share their experiences of delirium this research would never have been possible. I am very grateful to each and every one of these women for their open and sincere conversations, their time and their commitment to the study. Without this generosity it would not have been possible to enrich our understanding of their everyday world and better comprehend what delirium means to them. To these family members I say a heartfelt thankyou and trust that those who read this work will recognise the humanness of their experience and take the insights they gain to inform their health care practice.

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This dissertation is not just mine, but ours. I could not have come to this end without you all.
For my mum, Yvonne Squires.
Though passed, your love, strength and wisdom inspires and guides all that I do.
DELIRIUM: A PROGRAM OF RESEARCH

This thesis constitutes a major part of a program of research which focuses on delirium in older people. This research program commenced in 2007 with my involvement in a pilot study designed to test a participatory action research (PAR) approach to a range of problems associated with assessing, preventing and managing delirium in acute care settings (Day, Higgins, & Koch, 2008, 2009a, 2009b). This was followed a year later with a study designed to evaluate the outcomes of the PAR pilot study (Li, Giles, Dumont, Day, & Higgins, 2009). In 2009 I commenced my PhD candidature and continued to publish from these earlier studies, as well as the research described in this thesis (Day, Higgins, & Keatinge, 2011).

Journal Publications


Book Chapters


Conference Posters


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ABSTRACT

The study presented in this thesis provides a description and interpretation of the experiences of family members during their older loved one’s delirium. Fourteen women, aged 51 to 74 years, participated in the study and, over an interview period of nineteen months, described their experiences. These twelve daughters and two wives supported and cared for their loved one at home, in residential aged care and/or while hospitalised.

The approach used to explore the women’s experiences was existential phenomenology, informed by the philosophies of Sartre and Merleau-Ponty. Changing family portraits: Sudden existential absence during delirium depicts the women’s experiences during their older loved one’s delirium. Existential absence for these women was experienced as the sudden absence of their familiar older loved one and the arrival of a stranger. The meaning of existential absence is further represented by the theme Living the fragility of a loved one’s presence and the sub-themes Facing a loved one’s existential absence and Living with a stranger, as well as the theme Living life holding on and the sub-themes Waiting for a loved one, In the dark, On the fringe but centre stage, On thin ice, and Keeping secrets. These themes describe the unexpected and distressing nature of their loved one’s absence during delirium, and how difficult it was for the women to cope and await their loved one’s return.

The description and interpretation presented in this thesis reveals the profound impact of family member experiences during their older loved one’s delirium. It establishes the importance of health care staff appreciating family member experiences and relates the insights gained to health care practice, suggesting how family member experiences can inform ways health care staff include family members in their older person’s care and provide compassionate, sensitive support during delirium.
KEY

The conventions described in the “Publication Manual of the American Psychological Association (6th ed.)” (American Psychological Association, 2010) have primarily been adopted in this thesis. However, two exceptions arise. The first through the use of italicised text where phenomenological terms are used more than once, so indicating the nature of the meaning intended. The second arises in relation to participant data, in which case the following conventions have been used.

Names
Pseudonyms have been used to refer to participants, as well as people and places referred to. Generic terms have been used to refer to health care staff.

Indented italic text
Long participant transcript excerpts.

“Italicised text”
Short participant transcript excerpts within text paragraphs.

[Plain type in square brackets]
Comments within participant transcript excerpts to provide clarification or explanation.

...
Material leading into the excerpt or the remainder of the participant’s sentence has been omitted for clarity and concision.

---
Short pause in the participant’s conversation.

[...]
Material has been omitted from within transcript excerpts for clarity and concision.

[pnumber]
Participant number.

(Name [pnumber] – Inumber – pnumber)
Ownership and location of participant transcript excerpts, with “p” referring to the participant number, “I” to the interview number and “p” to the paragraph number.

pnumber/number
Excerpts that continue across transcript paragraphs.
CHAPTER 1: STUDY INTRODUCTION
Chapter Introduction

Delirium is a serious but common condition that manifests in older people when they are unwell. In older people who are admitted to hospital the prevalence of delirium has been found to range from 10% to 31% (Siddiqi, House, & Holmes, 2006), however the incidence during hospitalisation can be as high as 53% (Bruce, Ritchie, Blizard, Lai, & Raven, 2007; Dasgupta & Dumbrell, 2006). In residential or long term aged care the prevalence of delirium can also be high, at times up to 70% (de Lange, Verhaak, & van der Meer, 2013). When delirium develops the older person’s usual demeanour changes; they behave in ways that are out of character or even bizarre, and seem to inhabit another world, changing to such an extent that the older person becomes strange and unfamiliar to family members (Stenwall, Sandberg, Jönhagen, & Fagerberg, 2008).

In light of how common delirium is when an older person is unwell, and by virtue of love, a sense of duty, roles or responsibilities, family members of older people are likely to encounter their loved one during delirium and the changes that ensue. Despite the high prevalence and incidence of delirium in older people, little is known about the experiences of family members during this time. Without an understanding of these experiences it is difficult for health care staff to respond with compassion, provide meaningful support and appropriately include family members in their older loved one’s care. Whether or not family members are at home with their loved one or visiting them in residential aged care or acute hospital wards, it is important for health care staff to understand the experiences of family members and take this challenging and often difficult experience into account during care.

The study described in this thesis emerged from my concern for family members when their older loved one had delirium. My concern was about what family members thought and felt when their loved one changed so suddenly and profoundly that they were no longer familiar or recognisable (Stenwall, Sandberg, et al., 2008).

The discussion that follows sets the scene for the study undertaken to address my concerns. It describes how I became interested in the experiences of family members and presents the study background, its justification and purpose. The discussion also includes an outline of delirium as a condition experienced by older people, definitions of key terms and a description of how the thesis is organised.
Why Explore the Experiences of Family Members?

My interest in exploring family member experiences during delirium was initially aroused in 2007 when I became involved in a pilot participatory action research (PAR) study. This study considered care of the hospitalised older person during delirium (Day et al., 2008, 2009a, 2009b) by engaging with nurses who cared for older people. When listening to their accounts a strong and proactive orientation towards the needs of the older person was disclosed, including an interest in family members when they could help with care. These nurses described the presence of family members at the bedside and particularly staff’s reliance on them as a calming presence and a watchful eye during the older person’s periods of hyperactive behaviour and during busy shifts. The nurses also described being confronted with fearful and sometimes distraught family members, and feeling ill-equipped to know what to say or how to support them.

Participation in the PAR study prompted reflection on my past experiences as a family member, and led me to ask how PAR participant descriptions were different to my experiences caring for my mother when she was hospitalised with delirium. I recalled this as a difficult time; as a time when my mother was not herself and seemed to move away from me in a way that I had not experienced before. I worried about her and feared that she may die. She had been ill before but this time was strangely different. As the busyness of ward life and care went on around us, my mother remained very quiet, somewhat withdrawn. When gently roused she faintly smiled but had difficulty following what was said. She was conscious and initially, seemingly, comprehended what I said, but she was not really present for me or with me; not even for little asides that before might have brought an instant smile and quick cryptic reply. The nursing staff seemed “happy” with how my mother was and I thought somewhat relieved that I was there so often since she needed help with the most basic activities. I would sit with her in the quiet of her single hospital room, helping her to eat, one small spoonful at a time with lots of prompting to chew and swallow. She seemed to just get lost within each mouthful. Not asleep; awake but not with me. I wanted to be near her, hoped for improvement but feared the worst. The nurses came and went but did not seem to notice that my mother was changed as a person. They focused on medications, her drips and her wounds as I waited for my mother’s familiar responses.

My experiences engendered an interest in exploring the lived experience of family members, particularly family members who encountered an older family member, their loved one, during delirium. As a nurse and a researcher I asked and wondered what it was like for other family members to be with their older loved one at this time. I asked;
What sense do other family members make of the changes in their loved one? and What meaning does this have for them? Do they find the changes unexpected as I did? Do they go unnoticed, perhaps relegated to the insidious and unstoppable changes of ageing, dementia, or the effects of treatment or medication?

My quest to more deeply understand the experiences of family members began with a search for experiential descriptions in professional literature (see Chapter 2: Literature Review). However, I soon realised that the voice of family members was almost silent. This seemed amiss given the prevalence and incidence of delirium in older people (as noted previously and detailed more fully later in this chapter), and care philosophies which include family members in care of the older person. The lack of research into the experience of family members during delirium strengthened my resolve and interest in bringing family member perspectives to the fore, raising awareness of their experience and providing insights that might influence care practices.

**Study Purpose and Research Question**

The purpose of this study was to explore the experiences of family members when with their older loved one during delirium. My interest was in exploring and understanding the perspective of family members themselves rather than counting or quantifying aspects of their experience, or privileging the perspective of proxies such as health care staff or researchers. As Merleau-Ponty (1945/2002, p. xviii) argues, each person perceives the world through their own perspective, making their view of the world uniquely theirs. Precisely because family members bring their own unique perspective, their experience may be hidden or unknown and unappreciated by health care staff. Reflecting this orientation the research question called for the family member’s perspective and asked “*What is the lived experience of family members who are with an older person when the older person has delirium*”? The related research questions were:

1. What do family members say about experiencing delirium in an older family member?
2. What are the thoughts, feelings and concerns of family members?
3. What impact do experiences of delirium have on family members?

Although it remains important for health care staff to develop an understanding of the uniqueness of each person they encounter, Cohen, Kahn, and Steeves (2000) argue that understanding the meaning of the same experience for similar people can provide a sensitive basis upon which health care staff can enter caring relationships.
Facilitating family members to describe their experiences and uncovering what it means to them to be with their loved one during delirium offers insights which can assist health care staff to understand the impact of delirium on family members, to thoughtfully engage with family members, appropriately involve them in care and provide sensitive support. Through improved understanding a compassionate basis can be established for health care staff to consider and respond to family members who are with an older loved one during delirium.

**Definition of Terms**

In studying the experiences of family members and concentrating on their perspectives it was important to define *family*. Exploration of the literature made it clear that there were different definitions, each changing the scope for study participants, their characteristics and contexts. For this study it was important to be guided by a broad definition of family membership so the study could remain open to participants with different relationships to the older person and yet had a close relationship with them. This stance reflected a movement away from a more traditional next-of-kin orientation and openness to diversity in family form.

Definitions of family embraced for the study view the family as a social group or network, inclusive of members who have relationships including and other than those defined by bloodline (e.g. mother, son, uncle, aunt, cousin), law (e.g. spouse), role (e.g. carer) or living arrangements. This perspective recognised felt connections within family groups, a distinction important to being inclusive of family members who, due to different cultural backgrounds and social or economic circumstances and preferences, define family relationships in different ways. Therefore the following definitions were adopted.

The family is a self-identified group of two or more individuals whose association is characterised by special terms, which may or may not be bloodlines or law, but who function in such a way that they consider themselves a family. (Whall, 1986, p. 241)

[A family is] a felt network of relationships. An evocation of a certain kind of interconnection that grounds, roots and nestles (...) It always provides a fundamental relatedness that doesn’t depend upon attraction or compatibility. (Moore, 1940, pp. 71-72)
Rather than terms such as *elderly, aged, seniors or geriatric, older person* has been adopted in this study to refer to people aged 65 years and older. This term reflects the way I value older people; excluded terms portraying negative, biomedical or ageist views which suggested lower human worth or decline. In addition, participants in this study referred to their older family member as a special person in their life; their loved one, reflecting strong connections. Therefore the terms *loved one* and *older loved one* have also been used.

**Understanding the Phenomenon Being Studied**

Family members play a key role in maintaining the health of individual family members by helping to prevent illness, promoting recovery and assisting adaptation to long term disability (Reed, 2006). Caring and providing essential support, be it during wellness or during delirium, is a central family role (Canadian Coalition for Seniors’ Mental Health, 2006; Stuart, 1991; vom Eigen, Walker, Edgman-Levitan, Cleary, & Delbanco, 1999). Family members continue in these roles when they are with their unwell older loved one, however, these roles have added importance. Family members provide essential emotional and social support, an impetus for recovery and act as a care resource, so sharing the burden of their older loved one’s condition and hospitalisation (Hall & Maslow, 2007; Hallberg, 2002; Higgins & Cadd, 1999; Laitinen, 1993; Lindhardt, Bolmsjo, & Hallberg, 2006; Stuart, 1991). However, their loved one’s illness affects more than the older person (Berkman, 2008; Hallberg, 2002). In pursuing their roles family members are impacted, encountering changes to interpersonal relationships and experiencing worry, strain, stress, distress, anguish, communication difficulties, a loss of intimacy or role disruptions (Grover & Shah, 2011; Hallberg, 2002; Li, 2005; Li, Stewart, Imle, Archbold, & Felver, 2000; Rutledge, Donaldson, & Pravikoff, 2000; Whitis, 1994).

**Delirium: Definition, Characteristics and Types**

Family members are impacted during delirium as their older loved one suddenly changes and is no longer like themselves (Andersson, Knutsson, Hallberg, & Norberg, 1993; Stenwall, Jönhagen, Sandberg, & Fagerberg, 2008; Stenwall, Sandberg, et al., 2008). When the older person has a sudden change in their alertness and/or behaviour, a change that is not expected with or without prior dementia, delirium is suspected (Anderson, 2005). According to the Diagnostic and Statistical Manual of Mental Illness (version 5) (DSM-5) delirium occurs rapidly, over hours or within a few days (American Psychiatric Association, 2013). The essential feature is “a disturbance
of attention or awareness that is accompanied by a change in baseline cognition that
cannot be better explained by pre-existing or evolving neurocognitive disorder”
(American Psychiatric Association, 2013, p. 599). This disturbance to the older
person’s cognition impairs their ability to direct, focus, sustain and shift attention
(American Psychiatric Association, 2000, 2013). There are also changes in memory,
orientation, language or disturbances in perception (American Psychiatric Association,
2013). The acute changes in the older person fluctuate during the day (American
Psychiatric Association, 2013), and are not a sign of normal ageing, nor a normal
response to hospitalisation or surgery (Lipowski, 1990). Delirium differs from other
cognitive conditions in older people because it is not an endogenous illness; rather
delirium develops as a result of an underlying medical condition or substance
(American Psychiatric Association, 2013; Fann, 2000), and indicating that the older
person is seriously ill (Inouye, Schelesinger, & Lydon, 1999; Lindesay, Rockwood, &
MacDonald, 2002; Lipowski, 1983). The changes to the older person’s cognitive and
functional capacities can make it difficult for family members to be with their loved one
and understand what has, and is, happening to them (Stenwall, Sandberg, et al.,
2008).

As the onset of the changes delirium brings in older loved ones is rapid, family
members may feel they come from nowhere. As these changes also tend to fluctuate
during the course of the day (American Psychiatric Association, 2013), a sense of
unpredictability can be created. As the older person’s perception may seem altered or
hazy and they may not be able to spontaneously orient themselves to new situations
(Aita, 1968), family members may find their loved one is easily distracted, more difficult
to engage in conversation or may be unable to move on from their previous answer
(American Psychiatric Association, 2000). Perceptual disturbances such as
misinterpretations, illusions or hallucinations may be present (American Psychiatric
Association, 2013), confronting family members with a world that does not seem real
and is bizarre, possibly even frightening. Behaviours may be worse at night and there
may be swings in emotion including fear, anger, depression and euphoria (American
Psychiatric Association, 2013; Miller, 2008).

The uncharacteristic changes that ensue during delirium may be confronting and
distressing for family members. Behavioural changes range from hyper vigilance,
restlessness or irritability, combativeness and repetitive behaviours (e.g. wandering) in
the hyperactive delirium subtype, to uncharacteristic quietness, somnolence, apathy, or
withdrawal in the hypoactive subtype (American Psychiatric Association, 2000). The
older person’s behaviour may also oscillate, mixing both hyperactive and hypoactive
behaviours throughout the day (Meagher, O'Hanlon, O'Mahony, Casey, & Trzepacz, 2000; Sandberg, Gustafson, Brannstrom, & Bucht, 1999).

The hyperactive delirium subtype has a more overt presentation and is likely to be a very dramatic change in a family member’s loved one. Characterised by an increased response to stimuli and increased psychomotor activity the older person often perceives their environment as being hostile or threatening and they may be uncooperative, verbally and physically aggressive, or attempt to abscond (Inouye, 2004, 2006; Inouye, Foreman, Mion, Katz, & Cooney, 2001; Maher & Almeida, 2002). They may also be hyper-vigilant, restless or irritable and display repetitive behaviours such as wandering, picking at the bedclothes or pulling at bandages and drainage tubing (Andersson, Norberg, & Hallberg, 2002; Foreman, Wakefield, Culp, & Milisen, 2001; Maher & Almeida, 2002; O'Keefe & Lavan, 1999; Ski & O'Connell, 2006). Their older loved one may try to climb out over the end of their bed and remove their intravenous lines, all the time complaining about spiders on the bedclothes or a man looking at them. In hyperactive delirium the older person’s behaviours may be disruptive and they may unknowingly obstruct their own care (Andersson, Norberg, et al., 2002), potentially causing injury to themselves and other people, including their family members.

Unlike hyperactive delirium, hypoactive delirium is characterised by reduced alertness and reduced psychomotor activity, (Inouye, 2006; Kaplan, Palmer, & Roche, 2003; Maher & Almeida, 2002). The older person is uncharacteristically quiet or still, somnolent, apathetic, withdrawn, or unaware and may be misdiagnosed with depression or not diagnosed with delirium at all (Inouye, 2004; Inouye et al., 1990; Maher & Almeida, 2002). Like my experiences with my mother, the older person appears to have dozed off, is befuddled, pre-occupied or slow in concentrating on what is happening (Aita, 1968).

Given the unanticipated and uncharacteristic nature of the behaviour changes that occur during delirium, family members who are with their older loved one may have confronting and difficult experiences and they may themselves feel confused, vulnerable or burdened (Stenwall, Sandberg, et al., 2008; Williams et al., 1985). As the person they know may suddenly seem unfamiliar (Stenwall, Sandberg, et al., 2008), it is possible that their experiences will be distressing, potentially even more distressing than the experiences of the older person themselves or nursing staff (Agar et al., 2012; Breitbart, Gibson, & Tremblay, 2002; Grover & Shah, 2011; Hallberg, 2002; Shury, 2002). It is also possible that family members living through their loved one’s delirium
may suspect or fear that their loved one has “gone mad”, now has dementia, suffered brain damage or close to their death (American Psychiatric Association, 1999; Lipowski, 1990; Namba et al., 2007) (see Chapter 2: Literature Review). Depending on the severity of the changes to the older person’s demeanour, delirium may be more or less in the foreground of each family member’s experience (Hallberg, 2002).

**Differentiating Delirium, Dementia and Depression**

Family members who are with their older loved one during delirium may think they have suddenly developed dementia. Though impaired memory is common to both dementia and delirium, older people with dementia typically remain alert whereas those with delirium display fluctuating levels of alertness (Conn & Lieff, 2001). In addition, the onset of cognitive impairment is slower in dementia than delirium, and fluctuations in symptom severity that characterise delirium are not present (American Psychiatric Association, 2000). When older people already have dementia and develop delirium, there is a history of insidious cognitive decline prior to a recent and sudden change in behaviour and alertness (American Psychiatric Association, 2000; Conn & Lieff, 2001).

In addition, older people with dementia are less likely to experience hallucinations or illusions than those with delirium (Kane, Ouslander, Abrass, & Resnick, 2009). Importantly Trzepacz et al. (1998), in an early study of older patients admitted to a geriatric unit (n=61), concluded that there are only subtle differences in the clinical presentation of delirium in older people with and without dementia.

Though the most common and important differential diagnosis during delirium is dementia (American Psychiatric Association, 2000), family members may attribute the changes in their older person’s demeanour to depression (Edwards, 2003). Depression, like dementia, characteristically has an insidious onset and prior history, and contrasts with delirium’s acute onset; over hours or weeks (Insel & Badger, 2002). In addition, the older person’s mood tends to be consistent during depression whereas it is more labile during delirium (Insel & Badger, 2002). Though it is sometimes difficult to distinguish severe depression from delirium, if clinical assessments show that the older person’s cognitive impairment is mild compared to changes in mood, psychotic symptoms and psychomotor behaviour, they are more likely to be depressed than have delirium (Koponen, Rockwood, & Powell, 2002). The potentially grave consequences of misdiagnosing delirium as depression or dementia point to the importance of distinguishing these conditions in acutely unwell older people (Koponen et al., 2002).
Family Member Involvement in Care

Despite the sudden changes that delirium brings to older loved ones, family members become involved in their loved one’s care, perceiving a need to assist nursing staff to cope with their loved one’s different and often disruptive behaviours, consequent workload increases, safety fears and general ward disruption (Dahlke & Phinney, 2008; Hallberg, 1999; Rogers & Gibson, 2002; Segatore & Adams, 2001). Family member involvement in care during delirium is also advocated in consensus based delirium clinical guidelines, protocols and research as an important way of improving the therapeutic environment for the older person, and preventing, detecting, monitoring or managing delirium across care contexts (Australian Health Care Ministers Advisory Committee: Health Care of Older Australian’s Standing Committee, 2010; British Geriatric Society and Royal College of Physicians, 2006; Dahlke & Phinney, 2008; Flood & Buckwalter, 2009; Foreman, Mion, Tryostad, Fletcher, & NICHE Faculty, 1999; Harding, 2006; Rapp, 2001; Ski & O’Connell, 2006). Some clinical guidelines recommend health care staff involve family members by encouraging them to stay with their loved one and re-orientate, calm, assist, protect and offer support (Canadian Coalition for Seniors’ Mental Health, 2006). To assist with calming and orientation, family members may be encouraged to bring possessions familiar to the older person into care environments (e.g. family pictures, sleepwear and objects from the bedside) (Canadian Coalition for Seniors’ Mental Health, 2006; Rosen, 1994). Rosen (1994) argues that family members should sit close enough to touch and reassure their loved one that they are not alone. This involvement is, however, despite little being known about the experiences of family members during their older loved one’s delirium.

In recommending family involvement in care it is clear that many guideline recommendations are motivated by a focus on the older person, prevention, detection, monitoring or management of their acute illness (Keyser, Buchanan, & Edge, 2012; Rosenbloom-Brunton, Henneman, & Inouye, 2010), and use of family members as care resources (Carter, 1998). With this focus it is possible that health care staff may consider their interactions with family members to be only concerned with enhancing the older person’s recovery and timely discharge, rather than considering the concerns of family members themselves. An emphasis on benefit to the older person rather than the concerns of family members is important for the immediate health of the older person and responsibilities of health care staff. However, family member involvement in care and their needs requires equal consideration and should not be overlooked or minimised (Cuellar & Butts, 1999).
While caring for an older family member can be rewarding (Hallberg, 2002), a recognition that families differ in their capacity and preferences for involvement in an older person’s care is important (Bridges, Flatley, & Meyer, 2010; Laitinen, 1992). It cannot be assumed that all family members wish to be involved or are willing to provide care or support. In a qualitative study by Higgins, Joyce, Parker, Fitzgerald and McMillan (2007) the theme being there to provide support reflected how family members (n=10) viewed their roles during their older loved one’s hospitalisation. Similarly the main action of family members (n=6) in an earlier study by Li et al. (2000) was being there to provide emotional support. Earlier Laitinen (1993) reported that family members of older people saw themselves as providers of emotional support rather than completing tasks related to activities of daily living, a distinction not always appreciated or acknowledged by health care staff but necessary when understanding family member willingness and readiness to participate in their loved one’s care (Laitinen-Junkkari, Merilainen, & Sinkkonen, 2001).

Consistent with understanding family member roles and the impact of an unwell family member, contemporary literature highlights the importance of health care staff perceiving family members to be an integral part of quality hospital care and emphasise the value of providing support that meets family member needs (Collier & Schirm, 1992; Hallberg, 2002; Higgins & Cadd, 1999; Higgins et al., 1997; Lindhardt et al., 2006). It is argued that current health care models need to reflect care that is not only focused on the older person, but beyond them to family members (Bridges et al., 2010; Ekwall, Gerdtz, & Manias, 2008; Haesler, Bauer, & Nay, 2007; Hancock et al., 2003; Hoggins, Wade, & McCarthy, 1990). Li et al. (2000) suggests a partnership model between health care staff and family members whilst Bridges, Flatley and Meyer (2010) advocate a relationship-centred approach which focuses on the needs of the older person, family members and health care staff. Similarly Nolan, Davies, Brown, and Keady (2004) argue for a care orientation which moves beyond the individualism of person-centred care to relationship-centred models. Importantly Nolan et al. (2004) suggest that relationship-centred approaches need to take into account different individual subjective experiences or perspectives. Indeed, Hallberg (2002) argues that each family is a unique relational system.

Some delirium guidelines include recommendations that respect the role and needs of family members during older person delirium, in particular guidelines developed by the Canadian Coalition for Seniors’ Mental Health (CCSMH) (2006). Here the need for a therapeutic alliance with family members is considered to be part of providing the best care possible for older people, as is the need for involvement in care to be determined
for each family member. The feasibility of family member participation in delirium prevention has been explored by Rosenbloom-Brunton, Henneman and Inouye (2010). This study concludes that although active engagement of family members in prevention interventions is feasible, a therapeutic relationship and partnership need to be developed.

On the whole this literature makes it clear that there is more to providing quality care to older people than simply addressing the needs of the older person and considering family members to be care resources. Despite this evidence the needs of family members can remain overlooked, unknown or inadequately addressed by health care staff (Breitbart et al., 2002; Collier & Schirm, 1992; Higgins & Cadd, 1999; Higgins et al., 2007; Lindhardt, Hallberg, & Poulsen, 2008; Stenwall, Sandberg, et al., 2008; Yagil, Luria, Admi, Moshe-Eilon, & Linn, 2010).

**Family Member Needs and Support Interventions**

The needs and support interventions for family members who are with their older loved one during delirium is given little attention within the vast research literature on delirium in older people. As noted previously, this is despite clinical guidelines suggesting family involvement and health care models or care orientations which consider the family to be part of quality care for the older person. Reporting one of the few studies focused on family members when encountering an older loved one during delirium, Stenwall, Sandberg et al. (2008) argues that working to achieve mutual trust between the older person and family members is of utmost importance and suggests helping family members to encounter and understand the older person’s uniqueness. One guideline for the care of older people with delirium (Harding, 2006) notes the importance of negotiating family roles and ensuring these roles do not add to existing family burden. Van der Veld’s (2010) small interview study of relative’s needs during delirium (n=7) suggests that family members need written/verbal information about the nature and meaning of delirium, to be involved in care and receive advice on how to cope. This includes emotional and practical support which addresses how to cope with aggressive behaviour, agitation, disorientation and hallucinations. Providing honest information and education about delirium is often suggested as an intervention (Bull, 2011; Canadian Coalition for Seniors’ Mental Health, 2006; Hallberg, 1999; Harding, 2006; Kaplan et al., 2003; Registered Nurses Association of Ontario, 2010; Stenwall, Sandberg, et al., 2008). Rosen (1994) argues that family members need to be educated about the older person’s condition before they meet their loved one and instructed in reminiscence therapy. Guidelines from the Registered Nurses Association
of Ontario (2010) and CCSMH (2006) suggest that family member education has a dual purpose; helping family members to play a role in the detection, monitoring and management of delirium, and improving family member knowledge to reduce feelings of stress and burden. van der Veld (2010) emphasises the importance of offering opportunities to discuss their experiences after delirium passes and providing additional information and explanation about delirium. Noted is a need to tailor care to the perspectives of family members themselves. Importantly Hallberg (2002) argues that educating families is insufficient without an understanding of what it means to family members to have an older family member who is acutely confused and the problems family members face.

**Family Support Interventions: Delirium During Palliative Care**

Further insight into possible needs and support interventions for family members is gained from literature focused on family members who visit patients receiving palliative or advanced cancer care. These patients, like older people, often experience delirium (Casarett & Inouye, 2001; Centeno, Sanz, & Bruera, 2004; Lawlor et al., 2000). In adult palliative care contexts the prevalence of delirium at admission ranges from 26% to 42%, and is up to 90% in terminally ill patients (American Psychiatric Association, 2000; Breitbart & Alici, 2008; Casarett & Inouye, 2001; Leonard, Raju, et al., 2008; Robinson, 2011). In palliative and advanced cancer care literature the suggested support interventions are broad, there are few consistent suggestions to guide clinical practice and there is limited evaluation. Unlike literature focused on older people, there is a focus on caring to facilitate a peaceful death for the patient and family rather than correcting the underlying condition. Adjusting the environment so it becomes a favourable settings for family members, encouraging normal family routines and facilitating support from other family members are suggested by Namba et al. (2007). Unlike studies focused on family members of older people, one common suggested intervention for families is providing relief from physical care tasks (Morita et al., 2007; Namba et al., 2007), an intervention which aligns with family involvement preferences (Higgins et al., 2007; Laitinen, 1993; Li et al., 2000), and contemporary health care models (Bridges et al., 2010; Carr & Fogarty, 1999; Ellers, 1993; Hall & Maslow, 2007; Lindhardt et al., 2006). To achieve care relief Morita et al. (2007) suggests coordinating family member support and providing reassurance that health care staff can provide care. Explaining the pathology and expected course of delirium, management of agitation symptoms, making time to be with the family and being respectful of the patient’s subjective experience are also suggested (Morita et al., 2007). Robinson (2011) argues that during terminal delirium family members need the medical nature of
delirium explained, as well as treatment options. Multidisciplinary interventions and supportive psycho-educational interventions are recommended to alleviate family member distress and to allay any misconception that agitation is a sign of extreme pain, or that the person has lost their mind (Robinson, 2011). Whereas Morita et al. (2008) and Robinson (2011) suggest family education as a possible intervention, Gagnon et al. (2002) argues that family members may only benefit slightly from specific psychological and educational interventions about delirium in palliative care contexts. As a whole, palliative or advanced cancer care literature evidences a care orientation which is inclusive and supportive of family members, an orientation less apparent in studies focused on delirium in older people to date.

**Family Support Interventions: Hospitalised Older People**

Broader literature focused on family members of hospitalised older people also suggests interventions to address the needs of family members. Bridges et al. (2010) argues that family members are at risk of not having their expertise and contribution to the older person’s care recognised and valued, suggesting that family members benefit from interventions which help them to feel they are welcome, have reciprocal relationships with health care staff, are respected and cared for, and will receive timely help. Important to being respected is valuing family member knowledge of the older person and using this knowledge to inform care, as well as respecting the family member’s role (Bridges et al., 2010). Family members often expect emotional support through empathetic interest and the provision of honest, easy to understand and comprehensive information. However, family members often feel excluded (Astedt-Kurki, Paunonen, & Lehti, 1997), or afraid their requests for information will disturb nurses during their work (Laitinen, 1993). vom Eigen et al. (1999) identify emotional support, discharge planning, family participation and communication/information/education as the most problematic areas of family member experiences when their older loved one is hospitalised.

In coming to understand the phenomena being investigated it was not only important to consider the experience of family members during their loved one’s delirium, but also to consider the meaning of the word *delirium*. To help uncover varied meanings and their genesis I considered the etymological origins of *delirium* and variations in terminology.

**Delirium: Word Origins and Meanings**

When I contemplated what it was like to experience delirium I was struck by how this word had different meanings to different people and how, at times, the term was not
used at all. As noted by van Manen (2002), some words are used differently and sometimes indiscriminately in different contexts so that the meanings of words can change or be ambiguous. In order to apprehend these ambiguities I explored the etymological definitions and meanings of delirium.

The word *delirium* dates back in time to when psychiatry was in its infancy. It is derived from the Latin word *dēlīro*, meaning madness, and *dēlīrāre* meaning to turn aside from the furrow (*līra*, Latin for furrow), to deviate, to become deranged or crazy, or have “violent mental excitement” (Klein, 1966, p. 420). Since its early use delirium has consistently been related to a serious human condition with changes to mental competence and a poor prognosis. In tandem with its use as a medical or psychiatric term, delirium and its synonyms have become established in everyday language. Synonyms for delirium include *derangement, crazy, frenzy, fever, hysteria, insanity, lunacy, madness*, and *rage* (HarperCollins, 2013). Associated colloquial or idiomatic language has also developed, including *being out of one’s wits* (Bernaerts, 2009; Lipowski, 1990), *balmy* (Harding, Martin, & Holmes, 2008) and *in a second childhood* (Neville, 2008). Delirium, its synonyms and colloquial or idiomatic phrases, often elicit an association with an undesirable altered reality or reduced mental competence.

*Crazy*, a word often associated with delirium, has a long association with psychiatry and, in the past, described people who needed committal to an asylum. More recently crazy has been used as a derogatory name for people who are beyond reason, doing bizarre things and unable to stop their behaviours. For some time delirium has also conjured images of alcoholism and hallucinations during drug withdrawal (Aldhous, 2011). Paradoxically, delirium has been used to describe excessive excitability, an excited state of mind, or ecstasy, pleasurable states or highs that are sought after and enjoyed. These more positive meanings are reflected in modern media where delirium is used widely, at times referring to sudden frenzied corporate activities (Clow, 2006, October 19), the visual splendour of the Melbourne Cup (Anonymous, 2010), experiencing an open air theatre production (Hemming, 2010), being in love (Oliver, 2011), and the hectic but satisfying nature of modern life (Watson, 2011). What most of these meanings have in common with biomedical understandings is a direct link to the highs of delirium, particularly the motor activity which characterises hyperactive delirium (as describe earlier in this chapter).

Along with etymological definitions and meanings for delirium I also explored variations in health care terminology, adding further to my understanding of differences and similarities in meaning.
Delirium Terminology

Though *delirium* has been adopted as an agreed clinical and research term by the DSM (American Psychiatric Association, 2000, 2013; Kales, Kamholz, Visnic, & Blow, 2003), its use is inconsistent and conflicting in health care literature. Varied terminology includes a broad range of synonyms including *senile delirium, new onset delirium, mental confusion, intensive care unit syndrome or psychosis, organic brain syndrome, confusion, acute confusional state, reversible dementia, acute brain disorder or syndrome, sundowners, cognitive failure, altered mental status, and psychosis* (Fann, 2000; Granberg, Bergborn Engberg, & Lundberg, 1998; Harding, 2006; Lipowski, 1983, 1990; Morandi et al., 2008; Page & Ely, 2011; Stout & Gaviria, 2011; van Zyl & Seitz, 2006). In palliative care literature delirium can also be referred to as *terminal delirium, terminal restlessness, terminal agitation, opioid-induced neurotoxicity, agitated confusional state and cognitive failure* (Leonard, Agar, Mason, & Lawlor, 2008; Leonard, Raju, et al., 2008; Page & Ely, 2011), some terms implying delirium is linked to or is an inevitable part of dying. Within nursing literature the terms *confused, acute confusion* and *acute confusional state* are favoured (Fick & Foreman, 2000; Fleminger, 2002; Hare, McGowen, Wynaden, Speed, & Landsborough, 2008; McCurren & Cronin, 2003; Rapp, 2001; Rasmussen & Creason, 1991; Sendelbach, Guthrie, & Schoenfelder, 2009; Yevchak et al., 2012), at times combined with *disoriented* or used interchangeably (Rasmussen & Creason, 1991; Wolanin, 1977). Disorientation and an altered ability to interact are primary nursing indicators of confusion, with the presence of memory impairment, altered awareness of the situation, safety needs and aggressive behaviour supplementing this categorisation (Rasmussen & Creason, 1991). In nursing, confusion is a complex concept linked to many conditions (Rasmussen & Creason, 1991).

The reasons for using varied terminology are not clear. As no one medical specialty has responsibility for delirium management (Leentjens, MacLullich, & Meagher, 2008), it is possible that the use of inconsistent terminology stems from the condition’s lack of ownership within medical specialities. Fann (2000) suggests that the problem stems from delirium’s fluctuating clinical presentation whereas Agar et al. (2012) suggests nursing’s preference for confusion relates to their limited knowledge of delirium features. It is a concern that some research suggests that the use of confusion rather than delirium reflects a stereotypical view, one where confusion is part of normal ageing and/or undergoing surgery (Yevchak et al., 2012).
Although delirium terminology is varied, delirium has consistently been regarded as a grave or serious condition associated with acute physical illness, particularly illnesses causing fever or inflammation (Adamis, Treloar, Martin, & MacDonald, 2007). Its prominence in medical literature does however, contrast with the relative invisibility of this condition within the community and within the health care context. The reasons for this are unclear but possibly stem from patient reluctance to speak about their experiences, unclear terminology, diagnostic challenges or the many ways in which delirium presents (Davis & MacLullich, 2009). In addition, patients with delirium display symptoms which are associated with madness or alcohol intoxication, characteristics which historically attract societal prejudice or stigma (Brown, Fitzgerald, & Walsh, 2007). Other factors may be presumptions about age and cognitive decline (Neville, 2008).

Exploration of the origins and meanings for delirium brought to the fore different meanings and use. Some of these meanings were hidden before the study and uncovering them promoted reflection on the way delirium is used in everyday conversation, in health care contexts and in the study. It suggested alternative ways of knowing delirium and required meanings to be questioned and pondered. The possibility of differences in meaning when used by family members was raised and required consideration, particularly during participant recruitment and interviews, aspects of the study described in Chapter 4: Study Design and Methods. To respect the importance of clear terminology, distinguishing delirium from other states of confusion and to clearly orientate the study to the acute and potentially reversible condition described in the DSM-5 (American Psychiatric Association, 2013), the term delirium is adopted in this thesis rather the synonyms used in clinical practice and identified previously.

The discussion now moves to consider the prevalence and incidence of delirium in older people in greater depth, and literature published on delirium as a condition in older people. This discussion presents understandings which take a scientific or disease perspective, disclosing positivist ways of understanding delirium. Within this discussion it is noted that delirium frequently co-exists with dementia (Edlund et al., 2007). Whilst this type of knowledge is peripheral when considering lived experiences, it is important as a background and context for understanding the experience explored by the study and when making participant recruitment decisions. Importantly, these understandings were later set aside so that the existential nature of the experiences of family members could be explored and understood from the perspective of family
members themselves, a research activity consistent with existential phenomenology (see Chapter 3: Guiding Approach and Chapter 4: Study Design and Methods).

**Delirium: A Common Condition in Unwell Older People**

The worthiness of research into the experiences of family members during their older loved one’s delirium is reinforced by the common occurrence of delirium, as noted previously, and its association with acute illness and dementia. The prevalence of delirium in older people needing medical care has consistently been reported as high, ranging between 10% and 31% at the time of hospital admission (Siddiqi et al., 2006). Furthermore the incidence of delirium during medical care is reported to range between 3% and 29% (Siddiqi et al., 2006). High delirium incidences are reported in particular older patient populations, such as those with pre-existing dementia or receiving intensive, postoperative, or palliative care (Alici & Breitbart, 2009; Anderson, 2005; Bucht, Gustafson, & Sandberg, 1999; Caraceni & Simonetti, 2009; Cole, 2004; Cole & Soucy, 2003; Fick, Agostini, & Inouye, 2002; Inouye, 1998, 2006; Pisani, McNicoll, & Inouye, 2003; Voyer, Cole, McCusker, & Belzile, 2006).

The occurrence of delirium in older patients receiving intensive care is high, with 31% of patients reported to be in delirium at admission, and a further 31% of older patients developing delirium whilst in intensive care (McNicoll et al., 2003). Studies also suggest that delirium often occurs in older people post-operatively, incidences ranging between 4% and 53%, with higher incidences occurring after hip fracture and aortic surgeries (Bruce et al., 2007; Dasgupta & Dumbrell, 2006; Inouye, 2006). In adult palliative care contexts the prevalence of delirium at the time of hospital admission ranges between 26% and 42%, but can be up to 90% for patients who are terminally ill (American Psychiatric Association, 2000; Breitbart & Alici, 2008; Casarett & Inouye, 2001; Leonard, Raju, et al., 2008; Robinson, 2011).

Over time delirium has also been considered common in older people living in residential aged care settings (McCusker et al., 2011a, 2011b), however current data varies. Some sources indicate that less than 20% of older people in residential aged care have delirium (National Institute for Health and Clinical Excellence, 2010), others up to 70% in dementia specific services (American Psychiatric Association, 2000; Voyer, Richard, Doucet, & Carmichael, 2009). In a recent Canadian study (McCusker et al., 2011a) the prevalence of delirium in residential care residents (aged 65 years and over) at baseline was 3.4% for residents with a Mini Mental Status Examination (MMSE) score of 10 or more (n=204), and 33.3% for those with a MMSE score lower
than 10 (n=75). Pre-existing dementia, a predisposing factor for delirium (Inouye & Ferrucci, 2006; Robertsson, Blennow, Gottfries, & Wallin, 1998), is thought to increase the risk of delirium in older people by at least a factor of four (Inouye, 2004; Working Group for the Faculty of Old Age Psychiatry, 2005), suggesting a possible reason for the higher prevalence of delirium in residential aged care settings specialising in dementia care.

A clear picture of delirium prevalence and incidence in older Australian populations is still unfolding. Speed (2007) reports the prevalence of delirium in patients on medical and surgical wards (n=15) in two Western Australian hospitals. Of the patients surveyed (n=1209), 48 had a confirmed diagnosis of delirium without dementia and 84 had delirium superimposed on dementia or an organic brain disorder (Speed et al., 2007). In addition, Caplan and Harper (2007) report an incidence of delirium in a small control group of older patients (n=21, aged over 70 years) in a geriatric unit as 38% (n=8). An earlier small orthopaedic unit study by Niam and Bruce (2005) reports a similar incidence of delirium (37.5%; n=10) in a group of patients (n=28) aged between 50–96 years (average age 82 years).

Importantly the reported occurrence of delirium in older people is thought to underestimate the problem (Collins, Blanchard, Tookman, & Sampson, 2010; Fann, 2000; Inouye, 1994; Schuurmans, Duursma, & Shortridge-Baggett, 2001), particularly for hypoactive delirium, a common and less recognised subtype of delirium in older people (Elie et al., 2000). There is substantial evidence that health care staff overlook or underrecognise delirium (Inouye, 1994; Inouye et al., 2001; Schuurmans et al., 2001; Steis & Fick, 2008), misdiagnose symptoms as dementia or depression and misattribute symptoms to the normal ageing process (Armstrong, Cozza, & Watanabe, 1997; Inouye, 1994; Inouye, Schelesinger, et al., 1999; Johnson, 1999). Underrecognition is thought to be the result of several factors, including the use of different diagnostic terms (Inouye, Schelesinger, et al., 1999; Johnson, 1999), a lack of knowledge and awareness of delirium (Schuurmans et al., 2001), the variable nature of delirium symptoms (Siddiqi et al., 2006; Young & Inouye, 2007), the subjective nature of diagnosis in clinical practice settings, a lack of experience in health care staff in assessing for changes in attention (Inouye, Schelesinger, et al., 1999; Johnson, 1999), frequent absence of baseline cognitive assessment data (Inouye, Schelesinger, et al., 1999; Johnson, 1999), and a failure by health care staff to appreciate delirium as a marker of severe illness and possible mortality (Inouye, Schelesinger, et al., 1999; Johnson, 1999). Wang and Mentes (2009) report patient characteristics, such as age, infection, hydration and hypoactive delirium increases the difficulty of detecting
delirium, however traditional Chinese values, such as respect for elders, hard work, modesty, non-competitiveness, and respect for tradition, were also noted as influencing factors. Collins, Blanchard, Tookman and Sampson (2009) suggests that delirium remains undetected in general hospitals due to the strong influence of diagnostic clouding created by the burden of admission co-morbidities whereas Page and Ely (2011) suggests that clinicians believe delirium simply reflects how critically ill the person is rather than being of importance in itself. Taking a diagnostic reasoning approach McCarthy (1991) suggests that nurses who make clinical judgments using a decline orientation are less likely to identify delirium in older people compared to nurses who use a healthful perspective.

Under-diagnosis and misdiagnosis of delirium as dementia potentially delays interventions for a treatable and serious condition in older people (Kamholz, 2010; Rockwood, Cosway, Carver, Jarrett, & Stadnyk, 1999), potentially adding to the distress family members can experience when with their loved one (Agar et al., 2012; Hallberg, 2002; Morita, Hirai, Sakaguchi, Tsuneto, & Shima, 2004; Namba et al., 2007). Without a diagnosis which accounts for the changes family members experience, they are likely to draw on their own understandings and may incorrectly relate what they witness with mental illness, dementia or a prelude to death.

**Continued Encounters with Delirium**

In the future it is likely that delirium will continue to be common in older people and continue to be encountered by their families in Australia and internationally. This is due in part to older age and dementia being un-modifiable predisposing factors for delirium in older people (Elie, Cole, Primeau, & Bellavance, 1998; Laurila, Laakkonen, Laurila, Timo, & Reijo, 2008; Lindesay, Rockwood, & Rolfson, 2002; Marcantonio, Flacker, Michaels, & Resnick, 2000; Martin, Stones, Young, & Bedard, 2000; Miller, 2008).

Australian population ageing trends suggest that the number of older people, aged 65 years and above, is likely to increase in the coming years (Australian Bureau of Statistics, 2009). These data indicate that the proportion of the Australian population aged 65 years and over is projected to increase between 23% and 25% by 2056 (Australian Bureau of Statistics, 2009). World population projections also indicate that there will be a continued transition to an aged population in future years (United Nations Department of Economic and Social Affairs Population Division, 2012). These projections indicate that the older world population is ageing, with those aged over 80 years expected to reach 20% of the world population by 2050, or 3.5 times more people than in 2012 (United Nations Department of Economic and Social Affairs
Population Division, 2012). The association between older age, particularly very old age, and delirium suggests that an increase in the number of older people in the population will also increase the number of older people likely to develop delirium and the number of family members who will encounter their loved one at this time.

The incidence of dementia in the Australian population is also expected to increase. As people continue to have longer life expectancy and the “Baby Boomer” population ages, the prevalence of dementia, including Alzheimer’s disease, is expected to rise (Access Economics, 2009). In 2009 it was estimated that 1.1–1.2% of the Australian population had dementia, however this proportion is predicted to increase to between 2.9–3.8% in 2050 (Access Economics, 2009). States with older population profiles, such as New South Wales (NSW), have higher incidence rates for dementia as a percentage of their state populations (Access Economics, 2005). For NSW, the state where this study was conducted, it was estimated that 84,000 people had dementia in 2009 and that this will increase by 410%, or to 341,000 people, in 2050 (Access Economics, 2005). As dementia has been identified as a major predisposing factor for the development of delirium (Elie et al., 1998; Juliebø, Bjoro, Skovlund, Ranhoff, & Wyller, 2009; Robertsson et al., 1998), an increased prevalence of dementia in the Australian population is likely to increase the number of older people who experience delirium, particularly when combined with population aging.

**Why Older People Have Delirium**

Some of the questions that family members might have during their older loved one’s delirium are; What has caused my loved one to change so suddenly and so profoundly? and Why is my loved one behaving so differently?

Advancing age has historically been considered synonymous with progressive cognitive decline and similarly delirium in older people was thought to be inevitable and untreatable (Foreman, 1993; Yevchak et al., 2012). While this tenet is no longer accepted, the aetiology and pathophysiology of delirium continues to remain unclear (Alagiakrishnan & Wiens, 2004; Fong et al., 2006; Fong, Tulebaev, & Inouye, 2009; Laurila et al., 2008; Miller, 2008; Trzepacz & van der Mast, 2002; van Muster, De Rooij, & Korevaar, 2009). Understanding delirium has become a complex task partly because delirium is a consequence of diverse and multifactorial aetiologies which often reflect the pathophysiology of other acute medical conditions or substances and complex risk factor interactions (Fann, 2000; Fong et al., 2009). The multifactorial and cumulative nature of an older person’s vulnerability to delirium has been illustrated by Laurila et al.
(2008), reporting that, on average, more than eight risk factors contribute to delirium in hospitalised older people.

It is thought that some older people are more likely to develop delirium than others, with risk factors often being separated into predisposing and precipitating groups (Inouye, 1994, 1998, 1999; Inouye & Charpentier, 1996). Factors present at the time an older person becomes unwell or enters hospital (predisposing factors) are thought to create an underlying vulnerability, and hospital, environment or care related factors (precipitating factors) are thought to impact on the older person during care, adding to their vulnerability (Inouye, 1999; Inouye, Viscoli, Horwitz, Hurst, & Tinetti, 1993; Schuurmans et al., 2001; Voyer, Richard, Doucet, Cyr, & Carmichael, 2011). Multiple predisposing factors have been identified for the development of delirium in older people, including advanced age, dementia/cognitive impairment, severe illness, fever, infection, metabolic and electrolyte imbalance, hydration, medications, functional impairment and pre-operative waiting time (Clegg & Young, 2011; Dasgupta & Dumbrell, 2006; Elie et al., 1998; Elmsthal, Wahlfrid, & Jerntorp, 1995; Inouye, 2000; Inouye & Charpentier, 1996; Inouye et al., 1993; Juliebø et al., 2009; Korevaar, van Munster, & de Rooij, 2005; Voyer et al., 2011). Dementia has been suggested as a major predisposing factor, with a recent study reporting a sixfold increase in the risk of delirium in older medical patients admitted to intensive care units (Pisani, Murphy, Van Ness, Araujo, & Inouye, 2007), and an earlier study reporting an increased risk of 40% (McNicoll et al., 2003). Cross sectional research into predisposing factors for delirium in long term care residents with dementia has reported age and severity of dementia to be key factors for delirium development (Voyer et al., 2009).

Many precipitating factors have also been identified. These include medications or medication increase, bladder catheter, cognitive impairment, cardiovascular disease, malnutrition, use of restraint, iatrogenic events and infection (Elie et al., 1998; Elmsthal et al., 1995; Inouye, 2000; Inouye & Charpentier, 1996; Inouye et al., 1993; Juliebø et al., 2009; Voyer et al., 2011). In addition, studies by O’Keefe and Lavan (1996) and Inouye et al. (1993) have demonstrated an inverse relationship between predisposing and precipitating factors, one whereby older people with high underlying levels of predisposition need only encounter minor precipitating factors for delirium to develop.

**Duration and Severity of Delirium**

Other questions family members are likely to have when they experience being with their loved one during delirium are; How long will the condition last? Will my loved one be the same once delirium passes? Understanding the duration and severity of delirium
is important for planning care and future decision making about ongoing care. For family members it helps them to understand how long they will need to relate to someone who is changed and no longer familiar (Stenwall, Sandberg, et al., 2008).

Delirium has traditionally been described as an acute reversible syndrome, implying a likely complete recovery (American Psychiatric Association, 2013; Blazer, 2008). However, the course of delirium is highly variable, ranging from hours or days to a more severe and prolonged deterioration that overlaps with dementia (Morandi et al., 2008). Although full recovery can be an outcome (Kiely et al., 2009; Marcantonio et al., 2000), a growing body of evidence suggests that recovery rates for older people are lower than originally thought, and persistent symptoms occur for longer periods than previously anticipated (Adamis, Treloar, Martin, & MacDonald, 2006; Cole, Ciampi, Belzile, & Zhong, 2009; Dasgupta & Hillier, 2010; Siddiqi et al., 2006). In a systematic review, Siddiqi, House and Holmes (2006) conclude that a significant proportion of hospitalised patients have persistent symptoms at the time of discharge, and at 6 and 12 months after discharge (Siddiqi et al., 2006). Similarly, a review by Cole, Ciampi, Belzile and Zhong (2009) reports that a significant proportion of older hospital patients have delirium at, and after, the time of they are discharged. A more recent review by Dasgupta and Hillier (2010) suggests that delirium persistence is associated with patient characteristics (e.g. dementia and number of co-morbid conditions), characteristics of the delirium episode (e.g. delirium severity and presence of the hypoactive delirium subtype) and the underlying acute condition (e.g. hypoxic illness).

In addition, Kiely et al. (2006) reports that older people with delirium that persists for less than 2 weeks are likely to achieve a recovery whereas those with delirium for more than 2 weeks are less likely to return to their baseline level of functioning. Older people who have prior dementia and develop delirium need more time for delirium to resolve than older people without dementia (Boettger, Passik, & Breitbart, 2009).

Reported delirium recovery findings challenge the reversibility characteristic of delirium described in past literature and the definition provided by the DSM-5 (American Psychiatric Association, 2013), suggesting that many older people may still have delirium when sent home, possibly for family to support or provide care. Alternatively older people without baseline dementia may return home or to their residential aged care setting with persisting cognitive deficits (MacLullich, Beaglehole, Hall, & Meagher, 2009). The transitory nature of delirium cannot be assumed and family members perhaps need help to cope, sustain their support for their loved one, to understand what is happening and to plan for the future.
It is important to note that not all older people suffer the same severity of delirium, suggesting that family members will have experiences of differing intensity. Voyer et al. (2007) reports that almost half of the older patients newly admitted to hospital from institutional care had moderate to severe delirium, and that prior cognitive function influenced the severity of their delirium.

Health Outcomes from Delirium

There is consistent evidence that hospitalised older people who have delirium also have poor health outcomes independent of important confounders, such as age, gender, comorbid illness, illness severity, and baseline dementia (Witlox et al., 2010). These poor outcomes potentially impact on family members during hospitalisation and after discharge, influencing their experience. Other than persistence of delirium (Anderson, Ngo, & Marcantonio, 2012; Cole, 2010; Cole et al., 2009), poor outcomes include cognitive decline or dementia (Davis et al., 2012; Fong et al., 2012; Krogseth, Wyller, Engedal, & Juliebø, 2011; Witlox et al., 2010), increased risk of death (Fong et al., 2012; McAvay et al., 2006), longer periods of stay in the hospital environment (Caplan, Coconis, Board, Sayers, & Woods, 2006; McCusker, Cole, Abrahamowicz, Primeau, & Belzile, 2002; Siddiqi et al., 2006), complications of hospitalisation such as pressure sores (Cole, 1999; Kaplan et al., 2003), or falls (Campbell & Buchner, 1997; Cole, 1999) and institutionalisation (Fong et al., 2012; Witlox et al., 2010). In several studies delirium has been identified as a significant independent predictor for mortality among hospitalised older people during the 12 months after hospital admission, even when there is no prior cognitive or functional impairment (Kiely et al., 2009; McCusker et al., 2002; Rockwood et al., 1999; Witlox et al., 2010). Furthermore recent research has suggested that mortality may vary with delirium subtype and presence of concurrent dementia (Yang et al., 2009). There is also mounting evidence that even when delirium is resolved, the older person has a vulnerability to repeat delirium episodes (Witlox et al., 2010), an aspect described by some family members in this study.

Care Approaches

Although effective interventions for the prevention of delirium have been identified (Akunne, Davis, Westby, & Young, 2013; Hempenius et al., 2011; Zhang et al., 2013), it is clear that not all delirium is preventable (Holroyd-Leduc et al., 2010; Inouye, 2000; Inouye, Bogardus, Williams, Leo-Summers, & Agostini, 2003). Care approaches therefore continue to have a focus on managing the older person once delirium has
developed and family members continue to encounter their older loved one during delirium.

Interventions used in health care settings to manage delirium have consistently focused on three simultaneous objectives; identification and treatment of the underlying cause, environmental modification and control or management of symptoms, and regular clinical review (American Psychiatric Association, 2000; British Geriatric Society and Royal College of Physicians, 2006; Brown & Boyle, 2002; Inouye, Bogardus, et al., 1999; Inouye, Schelesinger, et al., 1999; Kaplan et al., 2003; Lipowski, 1990; Michaud et al., 2007). At a hospital ward level emphasis has also been placed on enhancing nursing care and the ward environment to meet the specific needs of the older person, particularly managing hyperactive behaviours and disorientation (Young, Leentjens, George, Olofsson, & Gustafson, 2008). These objectives are reflected in a broad range of clinical guidelines and protocols for delirium (American Psychiatric Association, 1999; Harding, 2006; Rapp, 2001).

Given the complex nature of delirium in older people, the varied ways delirium presents clinically and the multiple underlying risk or causative factors, it is not surprising that there is consensus that the management of delirium needs to be based on the use of multi-component approaches that augment usual hospital care and target amenable predisposing and precipitating factors (Bogardus et al., 2003; Inouye, Baker, Fugal, & Bradley, 2006; Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000; Inouye, Bogardus, et al., 1999; Milisen, Lemiengre, Braes, & Foreman, 2005; Pitkala, Laurila, Strandberg, & Tilvis, 2006). Strategies incorporated into multi-component management approaches include monitoring and addressing oxygen saturation, blood pressure, pain, hydration and nutrition, urine retention and infection, constipation, temperature, mobility, adverse drug effects, vision and hearing, sleep quality and disorientation or anxiety (Cole et al., 2002; Cole, 1994; Lundstrom et al., 2005; Pitkala et al., 2006; Vidán et al., 2009). It is significant that these management strategies are very similar to those identified as successful in preventing delirium (Young et al., 2008). Though multi-component management approaches have demonstrated some effectiveness in reducing delirium duration, they are generally considered less effective for managing delirium than preventing its development (Milisen et al., 2005; Weber, Coverdale, & Kunik, 2004).

It is also disconcerting to note that some common hospital care practices, such as the use of one-on-one sitters and physical restraint, are without an evidence base (Flaherty & Little, 2011; Neville, 2006). In particular, studies (Boorsma et al., 2012; Inouye &
Charpentier, 1996) report that the use of physical restraint is associated with a greater risk of delirium and that physical restraint is linked to increased delirium severity (McCusker et al., 2001). Haloperidol, an antipsychotic drug, is currently used in short term pharmacological control of agitation in patients with hyperactive behaviours where these behaviours compromise safety or impede treatment, and when there is a known delirium cause or the patient is terminally ill (Alagiakrishnan & Wiens, 2004; American Psychiatric Association, 1999; Australian Society for Geriatric Medicine, 2005; British Geriatric Society and Royal College of Physicians, 2006; Fong et al., 2009; Jackson & Lipman, 2004; Michaud et al., 2007; Stagno, Gibson, & Breitbart, 2004). This is despite a recent systematic review indicating that the use of antipsychotics in the treatment of delirium in older hospitalised people is not supported by current research (Flaherty, Gonzales, & Dong, 2011).

The previous discussion has described delirium as a condition in older people, presenting the delirious older person as seriously ill, behaving in unfamiliar ways, and no longer able to make appropriate decisions, manage in a complex environment, self-care or problem solve (Kamholz, 2010). This description suggests that family members may be faced with difficult circumstances when they are with their older loved one, no matter which care setting they are in.

In the following discussion the broad context of the study is described. This is followed by a general overview of the study and a description of how the thesis is organised.

**Study Context**

The family members who participated in this study, described more fully in Chapter 5: Findings Prologue, were with their older loved one during delirium in a range of settings, most experiencing more than one setting during each episode of delirium. These included the family home or car, low care residential aged care services, hospital emergency departments and acute care hospital wards. Some of these settings were outside NSW in Australia, the state where the participants lived and the study was conducted. Unfortunately, as all but one family member participated in the study after their experience, it was not possible to access the varied settings where all the women experienced their loved one’s delirium. As most of the women were with their loved one when hospitalised at some time during their experience, I drew my understanding of the context of family member experiences from this setting. I therefore visited the three acute care hospital wards which were involved in participant recruitment; general older person medical care, orthopaedics and emergency transition
care of the older person. Consistent with the settings of the women’s experiences, none of these acute care wards specialised in delirium care.

During my visits to the acute care hospital wards it seemed that delirium was not widely acknowledged by nursing staff nor recognised as an important condition in older people. It seemed that the busy nature of acute hospital practice was focused on the management of confused older people and provided little opportunity to attend to delirium prevention and identification. As noted during prior involvement in the PAR study (Day et al., 2008, 2009a) the nurses preferred to say confusion or dementia when an older person displayed behaviours that made them difficult to care for. Although the hospital involved in the study had a brochure on delirium for family members, nursing staff did not talk about its use as part of their practice. This leaflet described what family members could do to help the older person and delirium as a medical condition, including a possibility that the older person may be unable to recall their experience or may remember being frightened and distressed (Hunter New England and NSW Health, n.d.). In addition, a delirium assessment tool\(^1\) was available, however nursing staff considered use of this tool to be part of the Dementia and Delirium Acute Care Clinical Nurse Consultant’s role rather than their own. At times the topic of delirium generated an emotional response from health care staff; some talking about how sad is was for the older person, others about how frustrated or unsafe they felt. When the frequency of delirium in older people was raised the nurses seemed divided; there were those who believed in the significance of the problem and others who remained sceptical about its importance; those that advocated prevention and those that worked on managing delirium once it had developed. It seemed that many staff members thought delirium was inevitable in older people or, because the older person was confused, delirium was no different to dementia.

Pockets of interest and commitment to addressing delirium for older people were however apparent. This interest often relied on local champions or clinical experts, making their impact heavily reliant on their presence on the ward or personal alliances. When local champions and clinical experts changed roles, the focus on delirium seemed to become diluted or lost; often lost to assumptions about dementia and cognitive changes with ageing. As the study progressed greater interest in delirium became apparent at the participating hospital wards, perhaps derived from the uptake of delirium guidelines or as a result of this or other research being conducted in the hospital (Li et al., 2009).

\(^1\) The Confusion Assessment Method (CAM) tool is explained in Chapter 4: Study Design and Methods)
At the time of the study other Australian hospitals and health services also had information brochures on delirium for family members. For example, “Information For Family And Friends Of Patients With Delirium” from St Vincent’s Hospital in Sydney (Consultant Liaison Mental Health Service, 2007) and Liverpool Hospital’s “Delirium In The Older Person: Information For Family And Community Service Providers” (Liverpool Hospital Aged Care Services, 2004). It is of concern that the content of these family education brochures, like the one from the acute hospital wards visited, offered no or little information that might help family members to understand what their experience could be like and how to cope, focusing instead on delirium as a condition, health service perceptions of family member roles or how they can help care for their loved one. The use of these Australian resources in clinical practice and usefulness to family members has not been evaluated and published.

Before the study commenced numerous guidelines for the prevention and management of delirium in older people were available nationally and internationally. International guidelines included the “Practice Guideline for the Treatment of Patients with Delirium” (American Psychiatric Association, 1999), “Guidelines for the Prevention, Diagnosis and Management of Delirium in Older People: Concise Guidance To Good Practice Series, No. 6” (British Geriatric Society and Royal College of Physicians, 2006), and nursing guidelines such as “Screening For Delirium, Dementia And Depression In Older Adults: Nursing Best Practice Guideline” (Registered Nurse Association of Ontario, 2003). At the same time Australian guidelines included the nationally endorsed “Delirium In Older People: An Australian Government Initiative” guidelines (Harding, 2006) and “Clinical Practice Guidelines For The Management Of Delirium In Older People” (Clinical Epidemiology & Health Service Evaluation Unit, 2006). Later Australian delirium care pathways were endorsed (Australian Health Care Ministers Advisory Committee: Health Care of Older Australian's Standing Committee, 2010). While some of these guidelines focus on delirium in acute care settings others, such as “Clinical Practice Guidelines For The Management Of Delirium In Older People” (Clinical Epidemiology & Health Service Evaluation Unit, 2006), have been developed for use across health care settings. Despite the availability of these guidelines Watson, Brand, Watson, and LoGiudice’s (2009) identified that only one third of Melbourne hospitals had delirium management protocols, with publicly funded hospitals outperforming privately operated hospitals.
Completing the Study

To complete the study, family members who had experienced delirium in an older family member were invited to participate. I engaged the staff of three wards from an acute tertiary referral hospital in Australia to recruit family members of older people who had delirium. I also accessed a database of people interested in participating in research\(^2\) to recruit family members to the study. Ultimately I recruited 14 women as study participants. Subsequently I listened to and contemplated each woman’s experience, recorded aspects of their context and explored other sources of lived experience material to help me to understand the meaning of family member experiences. For example, I explored images of older people during delirium, poetry and songs that referenced delirium.

The approach adopted to guide the study was existential phenomenology, an approach that takes as its starting point the lived world of human beings (Luijpen & Koren, 1969/2010; van Manen, 1990). My decision to use this methodology came from existential phenomenology’s concern with the study of human lived experience within the life context of each person, challenging taken-for-granted understandings of experience and with drawing out meanings embedded in everyday human existence (Luijpen & Koren, 1969/2010; van Manen, 1990). The experiences described by family members are their perspective, a perspective intricately linked to their subjective reality and their world. During the study the world of each family member was viewed as significant and within this orientation each participant disclosed aspects of their life context and shared being present in the world during a specific time and in a specific place.

The study findings present a phenomenological description of the experiences of family members during their older loved one’s delirium, a description which makes explicit the meaning of these experiences for the women who participated in the study. As noted previously, Cohen et al. (2000) argues that although it remains important for health care staff to develop an understanding of each person they encounter in their clinical practice, understanding the meaning for several people who have experienced the same phenomenon provides a sensitive basis upon which a caring relationship can be built between family members and health care staff. By providing a portrayal of meaning that can help health care staff to understand the uniqueness of family members and their experiences, the meanings described from this study work towards

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\(^2\) The Hunter Medical Research Institute (HMRI) register of community members interested in participating in health related research (see Chapter 4: Study Design and Methods)
a better understanding of the subjective nature of illness experiences for family members. The described meaning provides health care staff with insights and experience-based practice understandings. With improved understanding health care staff are offered the opportunity to appropriately encourage family member participation in their loved one’s care and to provide sensitive supportive family interventions. The meanings which emerged in this study also have the potential to increase recognition of the family in care of the older person.

**Thesis Organisation**

The study is presented via seven chapters. Delirium in older people and the importance of exploring the experiences of family members was presented in this introductory chapter. A selective approach to the vast body of literature on delirium has been used in order to provide an overview of delirium and its significance to family members. Also included is a discussion of delirium definitions, meanings and terminology. In Chapter Two research literature related to the experiences of family members who encounter delirium is reviewed. This review was initially completed when planning the study, identifying and confirming a gap in understanding which required investigation. The primary area explored in this review is lived experiences during delirium, particularly the experiences of family members. Later in the study the review was revised to include experiences of losing a loved one’s self, so informing the discussion of study findings and study conclusions. In Chapter Three, existential phenomenology and its justification as the guiding approach for the study is presented. In this chapter I focus on the perspectives offered by Sartre (1943/2003) and Merleau-Ponty (1945/2002), how these philosophies guided the study to completion and aided interpretation of the experiences shared by family members in this study. The application of existential phenomenology through research design and the methods employed to explore the experiences of family members are detailed in Chapter Four. Here the transformation of existential phenomenology from a guiding approach to study design and methods is described. A discussion of challenges faced during recruitment of participants and ethical issues encountered in designing and conducting the study is also provided. Chapter Five presents a prologue, introducing study participants and their context. The findings of the study are presented in Chapter Six. Here a description of sudden existential absence conveys the meaning of the phenomenon of older person delirium for family members in the study. In the final chapter the findings of the study are discussed from a phenomenological perspective and alongside current literature and theoretical understandings of absence and losing a loved one’s self. Included is a
discussion of study trustworthiness and limitations. Study conclusions and their implications for health care practice and future research are also presented. Finally the appendices contain materials important to the conduct of the study, including copies of the human research ethics approvals, documents used during participant recruitment, interview question guides, and the undertaking required to secure transcriber confidentiality and security of interview data.

**Review and Summary**

In this chapter the background and context of the study have been described. In doing so the background to the study was presented along with a description of why the study was done, what I hoped to achieve and definitions of key terms. The discussion has also located the study within biomedical literature, a perspective which considers delirium to be a condition or illness in older people. A description of how the thesis is organised was also provided. The next chapter builds on this beginning and, in the early sections, reviews literature which reports experiences of older people during delirium. This includes experiences of family members, nurses and older people. Building further, the later sections of the next chapter consider literature on losing a loved one’s self, understandings fundamental to explicating the meaning of family member experiences during their older loved one’s delirium, implications for health care practice and recommendations for future research.
CHAPTER 2: NARRATIVE LITERATURE REVIEW - EXPERIENCES OF DELIRIUM AND LOSING A LOVED ONE’S SELF
Chapter Introduction

The previous chapter introduced the study and described its background and purpose. This prior description also located the study within literature which considers delirium to be an illness in older people. Chapter two builds on this beginning and, in the early sections, reviews literature which considers human experiences of delirium in older people. This signals a shift in interest from objective to subjective ways of understanding delirium, including a particular concern for the perspectives of family members. Building further, the later sections of the chapter consider literature which explores family member experiences of losing a loved one’s self during dementia and theoretical literature which considers the notion of losing a loved one’s self, or absence. These understandings were fundamental to discussing the meaning of family member experiences during their older loved one’s delirium at the study’s conclusion and were important to the study as older loved ones of several participants suffered pre-existing dementia.

Experiences of Delirium

This first section commences the narrative review and considers literature which reports research into experiences during delirium, paying particular attention to subjective human perspectives. This focus reflects an interest in, and search for, understandings different to the biomedical or empirical perspectives presented in the previous chapter, a perspective which dominates current research and literature on delirium in older people.

Taking a narrative approach, the review initially considers the perspective of older people; the people who have delirium and experience it as an embodied illness. For older people, delirium disrupts every aspect of their life and the lives of other people who share their situation, including nurses and family members. Delirium as experienced by nurses is then considered, disclosing the perspective of some of the people who provide health care during delirium. Finally, family member experiences during their older loved one’s delirium are discussed, providing insights into the perspective of people who were of interest to this study. This section identifies a scarcity of literature and minimal exploration of the experiences of family members. It includes research reporting delirium experiences for family members who were with their loved one during palliative or advanced cancer care, an approach which reflects participant experiences in the study and the contexts in which delirium occurs. As a whole the review paints a picture of the different ways delirium is experienced by
people with different perspectives on the situation and the meanings of their experiences. Common to all perspectives is distress, mistrust and difficulty in understanding and responding to different co-existing realities.

To achieve the narrative review described an electronic database search was undertaken using the search terms delirium, acute confusion, experience, older person, elderly, aged, geriatric, family, relative, spouse and carer. The databases searched included Medline, EMBASE, PsyclINFO, CINAHL, Proquest and Informit (Health Collection). To focus the search results the following strategies were used: Boolean logic, truncation, nesting and database subject headings. Multiple search term combinations were employed and all searches were confined to English language literature across the available time coverage for each database. Though this approach retrieved literature which may be considered old, it was considered important due to the scarcity of literature focused on the topic of interest. I was also interested in seeing if differences appeared over time, possibly with changes in health care or advances in understanding delirium from a biomedical or subjective perspective. Palliative care and advanced cancer results were included when focused on family member experiences during delirium as some participants in the study were with their loved one during palliative care and literature focused on older people was scant. As the particular focus for the narrative review was family member experiences during an older person’s delirium, particular emphasis was placed on critically reviewing literature reporting on these experiences. However, due to the scant literature a secondary focus was adopted which focused on the experiences of other key people at this time; older people themselves and nurses. Whilst the experience of other health care staff could have been included, literature on their experiences during older person delirium was minimal. Literature related to delirium in the settings of intensive care, high dependency or burns units were not a focus for the review. One thesis was excluded due to publication in Swedish and access to the results via English journals. Additional relevant literature was located by obtaining references cited in the retrieved literature. Clues and hunches derived from retrieved literature were used to inform searches for other literature using the worldwide web and Google™ as a search engine. Database and Google™ alerts were used to access and evaluate newly published research and other literature as it came to hand during the study. The literature in this review has been updated to August 2013.

In this narrative review search results are detailed under each of the perspectives considered; older person, nurses and family members. It is however worth noting that no meta analyses and few literature reviews were identified, a finding which reflects the
scant literature on this topic. It is also important to note that in the reviewed literature authors at times considered more than one human perspective. For example the study reported by Cohen and Pace (2009) considers patients and family members while Breitbart, Gibson and Tremblay (2002) considers patients, spouses/caregivers, and their nurses. Literature reviews by Bélanger and Ducharme (2011) and O’Malley, Leonard, Meagher, and O’Keeffe (2008) also consider more than one perspective. Because of their attention to multiple perspectives, these results are considered in more than one review section. In addition, the experiences of family members are at times described in research where this was not the primary consideration of the study or discussion. Due to the scarcity of research in this area these sources have at times been included. However, they have been used with caution as they often voice expert opinion rather than research findings. Consistent with a phenomenological approach to research, no reference is made to understandings gained from this literature review in the findings chapter. The findings chapter gives attention to the meaning of existential accounts shared by the women in this study. Theorising about the meaning of the women’s experiences was held in abeyance until later, as described in Chapter 4: Study Design and Methods and reflected in Chapter 7: Discussion and Conclusions.

To commence the narrative review, research exploring the experiences of older people during delirium is identified and discussed. This presents the perspective of the patient; the older person who has delirium and describes an inside view, a phenomenological notion described in Chapter 3: Guiding Approach. As Toombs (1993) suggests, this perspective considers illness to be fundamentally lived through by the person with the condition, creating a disruption that draws conscious awareness to the body in a particular way. The perspective shared by these older people is only indirectly available to other people who look on. Other than through accounts such as those in this review or shared recall, what it means to be the older person during an episode of delirium remains somewhat hidden at the time from other people, such as the women in this study.

**Older Peoples’ Experiences of Delirium**

In a small but growing body of research older people’s experiences of delirium are shared and explored. This research identifies that some older people are able to recall their experience and are willing to share what it was like once they have recovered. Schofield (1997), in an early grounded theory study involving interviews with older people who had recovered from delirium (n=19), reports that over half the participants recalled their experience. However, in a more recent questionnaire based study by
Grover and Shah (2011), just over a quarter of patients (n=53; aged 18-83yrs; mean 45.6yrs) who had recovered from delirium were able to recall being acutely confused. The recall evidenced by older people is despite the changes to consciousness and awareness that characterise delirium (American Psychiatric Association, 2013), how older people feel about their experience, and the difficulties experienced in incorporating what has happened to them into existing understandings (Harding et al., 2008). After delirium has passed some older people want to forget the episode, or are hesitant to discuss their experience, seeming to play down their unusual experiences and discouraging discussion (Harding et al., 2008). At times denial, embarrassment or dismissal of their experience is revealed through incongruent laughter or minimisation of what occurred (Harding et al., 2008). Older people’s varying ability or willingness to recall their experience is consistent with other patients who have had delirium, for example those of different ages and those receiving care in different settings, such as intensive care (Crammer, 2002; Granberg, Bergborn Engberg, & Lundberg, 1999; Grover & Shah, 2011; Laitinen, 1996; Minnick, Leipzig, & Johnson, 2001).

In the retrieved literature (see Appendix A), ten qualitative studies were identified which explored the experience of delirium from the older person’s perspective. These studies used different methodologies and were located in different settings, making comparison of their findings difficult (phenomenology n=4, interview n=3, non-participant observation n=1, interview and non-participant observation n=1 and grounded theory n=1). Study participants were mostly located in acute hospital orthopaedic (n=5) or gerontology wards (n=2) during their delirium. Most studies were conducted in Sweden (n=6); others were conducted in the United Kingdom (n=2), America (n=1) and New Zealand (n=1), further complicating comparison. Missing from these studies are the experiences of older people who have delirium when in Australian health care settings. Also missing are experiences situated in acute care settings other than orthopaedics (e.g. general medical or surgical care), home based care and residential aged care.

In addition to these ten qualitative studies, two reviews were identified which examined literature related to older person experiences of delirium, however both considered research beyond that reporting older person experiences. In addition, a quantitative study which explored patient distress during delirium considered patients who were not older people (Grover & Shah, 2011). More unusual, one self-report of delirium during renal failure was also retrieved. This collection of literature (n=14) provided an opportunity to consider older people’s experiences with those of family members and nurses. Importantly, they provide insights into how older people experience the
presence of family members during delirium, a perspective that forms part of the context of family member experiences.

**Another World**

Older people consistently describe suddenly finding themselves in an incomprehensible and contradictory world, one where they oscillate between different realities; present and past (Andersson, Hallberg, Norberg, & Edberg, 2002; Andersson et al., 1993), here and there (Andersson et al., 1993), dreaming and awake (McCurren & Cronin, 2003; Sorensen Duppils & Wikblad, 2007), or real and unreal (Andersson, Norberg, et al., 2002). Andersson, Hallberg et al. (2002), in a study grounded in phenomenology and involving older people (n=50; 67-96yrs) who developed acute confusion during hospitalisation, describes experiencing another world in the theme *Encountering past, present and the realm of imagination as reality*. Older people in this study described a mix of events from past and present that made them feel imprisoned in an imaginary or borderline state (Andersson, Hallberg, et al., 2002).

Delirium is also experienced as a state of fuzziness in which varied perceptual disturbances appear (Andersson, Hallberg, et al., 2002; McCurren & Cronin, 2003; Schofield, 1997; Sorensen Duppils & Wikblad, 2007). The perceptual disturbances can be beautiful, pleasant or entertaining (Schofield, 1997), or unpleasant and frightening (Andersson, Hallberg, et al., 2002; McCurren & Cronin, 2003; Schofield, 1997; Sorensen Duppils & Wikblad, 2007). Commonly recalled are visual hallucinations or illusions of people and animals (Andersson, Hallberg, et al., 2002; Fagerberg & Jönhagen, 2002; McCurren & Cronin, 2003; Sorensen Duppils & Wikblad, 2007). For some older people these perceptions seem real (McCurren & Cronin, 2003; Sorensen Duppils & Wikblad, 2007). Others are aware that they are not. When experienced as not real, older people describe trying to hide their perceptions and feelings from other people (Harding et al., 2008; Sorensen Duppils & Wikblad, 2007; Stenwall, Jönhagen, et al., 2008), struggling against their perceptions (Andersson, Hallberg, et al., 2002), remaining detached (Schofield, 1997), and feeling unable to change their situation (Andersson, Hallberg, et al., 2002; Andersson, Norberg, et al., 2002; McCurren & Cronin, 2003; Sorensen Duppils & Wikblad, 2007). Fagerberg and Jönhagen (2002), in their study grounded in descriptive phenomenology, describe how older people’s (n=5) perceptual disturbances are intermixed with experiences of having *Wide-open senses*. In this state older people felt hyper-alert and hyper-responsive to everything happening in their situation and yet unable to concentrate on any one specific thing (Fagerberg & Jönhagen, 2002). Attempts to escape from threatening perceptual disturbances were
described (e.g. wandering in the ward or climbing over bed rails) (Fagerberg & Jönhagen, 2002). Suspicion was also described towards family members, health care staff and other patients when these people didn’t believe older person accounts of a different reality (Fagerberg & Jönhagen, 2002).

Reported less often by older people are enjoyable experiences when encountering another world during delirium (Andersson, Hallberg, et al., 2002; Schofield, 1997; Sorensen Duppils & Wikblad, 2007). Sorensen Duppils and Wikblad (2007), in a qualitative interview study involving older people (n=15; >65yrs) having hip surgery, describe how some participant experiences were at times pleasurable or beautiful, contrasting with times when they were awful and frightening. Schofield (1997) reports pleasant and entertaining experiences in a grounded theory study exploring older person perceptions of an episode of delirium (n=19).

These experiential descriptions provide a sense of what is lived through by older people. Apparent are shifts and duplicities in the reality experienced. For older people their changing reality during delirium is like “A madman’s ravings [which] are absurd in relation to the situation in which he finds himself, but not in relation to his delirium” (Sartre, 1938/2007, p. 129).

**Broken Connections**

As older people report suddenly finding themselves in an incomprehensible and contradictory world, it is not surprising that communication is also described as problematic. Older people who are hospitalised during their episode of delirium describe perceiving a distance between themselves and other people in their situation (Andersson, Hallberg, et al., 2002; Sorensen Duppils & Wikblad, 2007). Described are difficulties in connecting with people who appear in hallucinations or illusions, as well as with health care staff or family members who are unaware of the older person’s changed world (Andersson et al., 1993; Sorensen Duppils & Wikblad, 2007). In Stenwall, Jönhagen et al.’s (2008) interview based study involving older people (n=7) from two geriatric wards, the theme *Feeling lonely within the perceived reality of an acute confused state* describes how older people feel dependent on their own ability to communicate with others and the willingness of other people to understand what is happening to them (Stenwall, Jönhagen, et al., 2008). Also described is a need to be equal in their interactions with other people; to be trusted by others and able to trust them (Stenwall, Jönhagen, et al., 2008). These older people emphasise the importance of health care staff and family members understanding what is happening to the older person when in their changed world (Stenwall, Jönhagen, et al., 2008).
Also described is how trust is fragile and can be broken when the older person feels their reality is questioned or mocked by health care staff or family. Mistrust and communication barriers between the older person and their family are disturbing and isolating (Stenwall, Jönhagen, et al., 2008). Problematic communication and mistrust during delirium are likely to impact on family members who are with their older loved one.

**Strong and Disturbing Emotions**

It is also not surprising that delirium is recalled by many hospitalised older people as a frightening event in their lives and time in a frightening world (Schofield, 1997; Sorensen Duppils & Wikblad, 2007). In their delirious world they describe encountering a sudden change of reality which gives rise to strong emotional feelings (O'Malley et al., 2008; Sorensen Duppils & Wikblad, 2007). Feelings described include fear, anxiety and being threatened (O'Malley et al., 2008), panic (Sorensen Duppils & Wikblad, 2007), frustration (McCurren & Cronin, 2003), mistrust (McCurren & Cronin, 2003; Stenwall, Jönhagen, et al., 2008), anger (McCurren & Cronin, 2003; Sorensen Duppils & Wikblad, 2007), and hatred (Andersson, Norberg, et al., 2002). Also common are feelings of loneliness, hopelessness and depression (Fagerberg & Jönhagen, 2002; O'Malley et al., 2008; Schofield, 1997; Stenwall, Jönhagen, et al., 2008). For some, feelings of fear are linked to both their experiences during the episode of delirium and to concerns about being delirious again (Andersson, Hallberg, et al., 2002; Fagerberg & Jönhagen, 2002; Sorensen Duppils & Wikblad, 2007). In Harding et al.’s (2008) study based on interpretive phenomenological analysis and involving older people after hip fracture (n=9), the theme *Struggling to understand the experience of delirium* describes how some older people associate their behaviours during delirium with madness or senility. As one participant in Harding et al.’s (2008) study says, “They might think I’m barmy... I think they’d be right” (p. 958). Similarly, older people (n=15; >65yrs) having hip surgery in Sorensen Duppils and Wikblad’s (2007) interview based study describe fearing admission to a mental health service.

McCurren and Cronin (2003), in a phenomenology based study of older people (n=14) receiving medical/surgical hospital care, describe a lack of trust from feelings of anxiety and confused reality in the theme *Responding to the confusion*. In this study older people also describe becoming angry and frustrated from the anxiety produced by their frightening experiences (McCurren & Cronin, 2003). Despite being in a frightening world, in Stenwall, Jönhagen et al.’s (2008) interview based study, older
people can feel safe and supported during delirium when family and health care staff understand the older person’s changed reality and trust the older person.

The experience of distress is consistently described by older people during delirium. Grover and Shah (2011), in a questionnaire based study using the Delirium Experience Questionnaire, report on a convenience sample of patients assessed by a psychiatrist to have delirium (n=53; aged 18-83yrs; mean 45.58yrs). Participants (n=15) who could recall their experience reported moderate (n=4; 26.7%) to very severe levels of distress (severe n=6; 40.0%; very severe n=5; 33.3%). These participants also described their delirium as a state of fearfulness (n=8), anxiety (n=4), confusion and feeling strange (n=7). It needs to be noted however, that participants in this study were not all older people, perhaps influencing reported distress levels and relevance to this study. Systematically reviewed qualitative literature also provides additional insight into the distress experienced by older people and how disturbing delirium is (O’Malley et al., 2008). Whilst O’Malley et al. (2008) identifies perceptual disturbances and delusions as the strongest source of distress for delirious patients, both during and after resolution of delirium, it needs to be noted that this judgement was largely based on the experiences of hospitalised patients with cancer rather than older people in particular.

Memories of Delirium

After delirium has passed a range of disturbing emotions are described by older people who recall their actions and words while delirious. Some express feelings of belittlement (Andersson et al., 1993), guilt (Fagerberg & Jönhagen, 2002), shame (Fagerberg & Jönhagen, 2002), embarrassment (McCurren & Cronin, 2003; Stenwall, Jönhagen, et al., 2008), humiliation (Fagerberg & Jönhagen, 2002), or remorse (Sorensen Duppils & Wikblad, 2007). At times they explain their actions as being out of character (McCurren & Cronin, 2003), or ask for forgiveness (Fagerberg & Jönhagen, 2002). Encountering memories of delirium can mean confronting the reality of their experience (Andersson, Hallberg, et al., 2002; Andersson, Norberg, et al., 2002; Fagerberg & Jönhagen, 2002), or viewing the episode as a dissociated event in their lives (Sorensen Duppils & Wikblad, 2007). Neville (2008), in a study using discourse analysis, explored family member, older person, and specialist staff experiences during delirium. Older people in this study described how during delirium they are treated as childlike or worthless, revealing ageist attitudes embedded in care decisions. For older people, discussing their experiences can risk being viewed as foolish (Harding et al., 2008). In contrast, Andersson, Hallberg et al. (2002) used phenomenology to explore older orthopaedic patient experiences (n=50) during an acute confusional state and
report that some older people find recalling their experience helpful, aiding understanding and providing a sense of relief. These reactions suggest family members may face unexpected rejection or dismissal when wanting to talk about delirium with their older loved one, and that older people who have experienced delirium may be vulnerable, needing continued family understanding and support after delirium has passed.

**Support**

How nurses can support older people and minimise their distress or other emotional reactions remains unclear, with suggested interventions at times conflicting in the literature. For example, orientation is suggested by Schofield (1997) but Fagerberg and Jönhagen (2002) argue orientation exacerbates isolation and feelings of hopelessness. Delirium guideline recommendations for family and nurses to orient the older person to their “here and now” are therefore at odds with the experiences older people describe (Day et al., 2011). As a whole there is a view that nurses should strive to understand the meaning of the experiences of older people during delirium, trust and believe the older person and provide support (Bélanger & Ducharme, 2011; O'Malley et al., 2008). Belanger and Ducharme (2011), in their literature review, suggest nurses seek out the meaning of delirium as a lived experience for older people and use interventions that meet the needs expressed. It is suggested that understanding and acknowledging what the older person experiences, explaining what is happening, including family in the provision of care and discussing what has happened may be possible ways of reducing suffering for the older person (Bélanger & Ducharme, 2011). As at least some older people have expressed a desire to discuss their experiences once they have recovered, opportunities could be provided for older people to debrief (Bélanger & Ducharme, 2011; O'Malley et al., 2008). However, caution is needed as the effectiveness of this strategy is unknown (O'Malley et al., 2008).

As there are only a few studies which report the experiences of older people during delirium there is a clear need for further research in both similar and dissimilar settings to that reviewed. For example, five studies were set in orthopaedic ward settings and used varied methodologies; however it is not clear how important this setting or orthopaedic procedures are for how delirium is experienced by older people. Similarly it is not clear how care philosophies (e.g. person-centred versus family-centred, acute care versus maintenance aged care) influences the experiences of older people during delirium. Also inadequately explored are interventions to reduce the negative impact of delirium experiences, such as feeling frightened (Schofield, 1997; Sorensen Duppils &
anxious or threatened (O’Malley et al., 2008), frustrated (McCurren & Cronin, 2003), untrusted (McCurren & Cronin, 2003; Stenwall, Jönhagen, et al., 2008), alone and helpless (Fagerberg & Jönhagen, 2002; O’Malley et al., 2008; Schofield, 1997; Stenwall, Jönhagen, et al., 2008). These areas are particularly worthy of future research as the experience of older people is distressing and expert opinion is guiding some care interventions in current delirium guidelines.

The emotions described by older people may be directed towards family members who share the situation, impacting on family member experiences during their loved one’s delirium. However, knowing that older people can recall their experience suggests that health care staff and family members should continue to treat the older person with understanding, compassion, respect and trust.

**Older Person Experience of Family Member Presence**

When recalling experiences of delirium older people describe the presence of family members, an aspect discussed in a small number of studies (n=4). McCurren and Cronin (2003), in a study grounded in descriptive phenomenology and involving older patients (n=14), report that family member presence is helpful to the older person when hospitalised for acute medical-surgical care and in delirium. Stenwall, Jönhagen, at al. (2008), in an interview based study involving older patients (n=7) from a geriatric ward, also report positive older person feelings of safety, comfort, support, happiness, consolation and mutual understanding when family understand and trust the older person. Older people also describe seeking help, and feeling reassured when family members were present and provided explanations (Andersson et al., 1993; Andersson, Norberg, et al., 2002; McCurren & Cronin, 2003). In Andersson, Norberg et al.’s (2002) orthopaedic ward non-participant observation study of older people (n=51; 67-96yrs; mean 84.6yrs), the themes *Trying to achieve clarity* and *Searching for help from others*, including family members, reflects the older person’s need to make sense of their experience while in delirium, and the help that family members can provide.

Positive experiences are, however, balanced by other feelings, possibly reflecting the oscillating nature of delirium and the different ways this influences the older person’s interpretation of their situation and relationships with others. Fagerber and Jönhagen (2002), in their study based on descriptive phenomenology and involving older patients (n=5; 68-90yrs) from a geriatric clinic, describe older people as experiencing shame, guilt, embarrassment and humiliation from knowing that their family members saw their uncharacteristic behaviour. McCurren and Cronin’s (2003) study, as noted above, describes how older people find delirium makes them feel angry and frustrated,
emotions which are expressed when family members are present. Stewnell, Jönhagen et al. (2008), in the study noted above, report that older people sometimes choose to distance themselves from family members if the older person’s reality is questioned and mistrust is felt. Attempts to re-orientate older people to the reality experienced by family or staff can lead to increased feelings of mistrust (Fagerberg & Jönhagen, 2002), or feelings of loneliness (Stenwall, Jönhagen, et al., 2008).

The presence of family during an episode of delirium is therefore experienced by the older person in a range of ways and raises the possibility that family members may experience hostility and rejection, be perceived as helpful or oscillate between the two. The experience of family members is likely to be that of being with a less or unfamiliar person (Stenwall, Sandberg, et al., 2008), and may be different to what is expected. From the perspective of older people family members should strive to understand the meaning of their older loved one’s experiences, provide support and trust or believe the older person and the world they describe (Bélanger & Ducharme, 2011; O’Malley et al., 2008).

In the following section consideration is given to research literature which explores nurses’ experiences of delirium. This changes the perspective from that of the older person who has delirium, to those who share the situation with the older person but look at them from the outside, a phenomenological perspective discussed in Chapter 3: Guiding Approach.

**Nurses’ Experiences During Older Person Delirium**

Delirium is a common experience for nurses who provide care for older people admitted for acute emergency, surgical, medical, palliative or intensive care wards (Breitbart et al., 2002; Hallberg, 1999; Rogers & Gibson, 2002). Our understanding of what it is like for nurses to experience older patients during delirium is informed by only a small group of qualitative studies using different methodologies (n=9; interview n=4, discourse analysis n=2, grounded theory n=2, phenomenology n=1) and conducted in Sweden, Canada, Taiwan, Ireland, Britain, New Zealand and Australia (see Appendix A). These studies are mainly set in acute care orthopaedic (n=3) and medical/surgical (n=2) hospital wards. Unlike studies of older people’s experiences one study of nurse experiences was set in a unit specialising in the care of confused older people. In addition to these nine studies, two quantitative studies were located; one which validated the Strain of Care for Delirium Index (SCDI) to measure the strain experienced by nurses caring for patients during delirium (Milisen et al., 2004), and the
other measuring nurse strain using the SCDI during care (McDonnell & Timmins, 2012). Furthermore two reviews were identified which included literature relating to the delirium experiences of nursing staff. Missing from these studies are a body of research which considers the experiences of nurses working in various Australian health care settings. Also missing are the experiences of professional and non-professional nurses and other health care staff, including medical and allied health staff. The pilot grounded theory study by Lou and Dai (2002) is given cautious attention in this review as the participant sample was small and theoretical saturation was not reached from interview data.

**Encountering and Caring for the Older Person**

Nurses in the reviewed literature describe caring for a delirious older person as evoking feelings of mistrust, and as an unforeseeable situation in which the high needs of the older person conflict with needs of other patients on the ward (Agar et al., 2012; Lou & Dai, 2002; Stenwall, Sandberg, Jönhagen, & Fagerberg, 2007).

During care nurses describe trying to use themselves as a therapeutic tool. In Stenwall et al.'s (2007) phenomenological study of nurses (n=10) caring for older confused patients, the theme *The unforeseeable encounter* describes how nurses may become frightened when they perceive delirious older people to be suddenly changeable, not knowing the duration, outcome or how the older person will react emotionally. In addition, the theme *Always being on guard* describes how nurses can rarely trust the older person and still remain responsible for them (Stenwall et al., 2007). In this context they strive for control but need to be flexible in their approach with the older person (Stenwall et al., 2007). The theme *Use oneself as a tool* describes how these nurses use themselves to encounter and connect with the confused older person (Stenwall et al., 2007). Also revealed by these nurses is how using themselves can fail as a tool, their approach becoming one of control (Stenwall et al., 2007). Orthopaedic nurses in Rogers and Gibson's (2002) interview based study describe a focus on patient safely, including five trial and error strategies to care for the older person; constant surveillance, elimination of underlying causes, human caring, reorientation strategies and strategies for disruptive behaviour. These nurses attempted to provide care which was gentle, calming and reassuring, and described watching from a distance when the patient was quiet (Rogers & Gibson, 2002). In contrast nurses interviewed and observed in Schofield, Tolson and Fleming's (2012) discourse analysis study in acute care viewed older people during delirium as running, moving bodies, a construction that impeded their normal nurse/patient interactions and relationships. The dominant
construction of delirious older people was as physically active, at times destructive, and frequently aggressive towards other people in their situation (Schofield et al., 2012).

**Impact of Older Person Delirium on Nurses**

Nurses caring for older people during delirium describe far reaching effects. These include stress, distress, safety concerns, increased workloads and a need for balance (Agar et al., 2012; Dahlke & Phinney, 2008; Lou & Dai, 2002; Rogers & Gibson, 2002; Schofield et al., 2012). Nurses relate their stress and distress to factors such as the unanticipated and fluctuating nature of delirium, witnessing delirium symptoms, experiencing aggressive or resistive behaviours, the resultant perceived increase in workload, conflicts in care priorities, an inability to complete care work, and an imperative to meet moral and legal obligations for patient safety (Agar et al., 2012; Hallberg, 1999; Lou & Dai, 2002; Rogers & Gibson, 2002; Schofield et al., 2012).

Dahlke and Phinney’s (2008) interview based study focused on nurse management and challenges when caring for older people during delirium, describing how much of their time was used to assess older people, deliver care and manage aggressive behaviours. Competing demands are felt between caring for the older person and providing care to other patients on the ward; other patients perceived by these nurses to be more acutely ill (Dahlke & Phinney, 2008). These nurses described feeling pressured to use time with older patients more effectively and so using strategies to create time away from the older person (Dahlke & Phinney, 2008). Similarly nurses in Rogers and Gibson’s (2002) interview based study with orthopaedic nurses and Lou and Dai’s (2002) pilot grounded theory study involving graduate nurses describe competing work demands and needing to keep a balance between caring for the delirious older person and other ward patients.

When trying to make care decisions, nurses caring for older people during delirium describe moral distress and lowered self-esteem (Dahlke & Phinney, 2008; Rogers & Gibson, 2002; Schofield et al., 2012). They describe feeling guilty or stressed about being impatient with the older person and about care decisions involving use of physical restraint (Rogers & Gibson, 2002). Furthermore they describe feelings of insufficiency, guilt, and being fearful of being misunderstood when the older person’s delirium resolves (Stenwall et al., 2007). Nurses acknowledge that at times they consider the delirious older person to have lower care priority than other patients (Dahlke & Phinney, 2008), or designating the older person’s care to casual staff who may be less able to meet their needs (Neville, 2006), findings that are disturbing given
the serious nature of delirium for older people, as noted previously in Chapter 1: Study Introduction.

Two quantitative studies related to nurse experiences of caring for older people during delirium were identified in this review. In the first study Milisen et al. (2004) validated the Strain of Care for Delirium Index (SCDI) as a tool to measure the strain experienced by nurses caring for patients during delirium. Content validity was confirmed using an expert panel. Internal consistency was 0.88 using Chonbach’s alpha (Milisen et al., 2004). The SDCI was applied by McDonnell and Timmins (2012) to investigate subjective burden on a random sample of nurses (n=800) from the nurses’ register in the Republic of Ireland. McDonnell and Timmins (2012) report that responding nurses (n=181; response rate 22.6%) experienced elevated levels of stress and strain, primarily when caring for older people with hyperactive delirium. The subjective burden was high (mean=2.97) and the hyperactive/hyperalert subscale suggested these patients were the most challenging to deal with (mean=3.41). The most burdensome patients where those who were uncooperative and difficult to manage (mean=3.58). These results support previously discussed findings which report the negative impact of older person delirium on nurses providing care.

**Safety Concerns**

Personal and patient safety are identified as practice issues from nurse experiences as older person behaviours during delirium can be violent or aggressive, and the older person can show both reduced judgment and increased strength (Hallberg, 1999; Rogers & Gibson, 2002; Schofield et al., 2012; Stenwall et al., 2007). In Rogers and Gibson’s (2002) interview based study orthopaedic nurses (n=10) describe being physically attacked and subject to different types of verbal aggression as fearful events. One nurse in this study said “It scared me at first but I learned to watch the [older person’s] hands and sometimes I take another nurse with me” (Rogers & Gibson, 2002, p. 14). Stenwall et al. (2007), in their phenomenological study of nurse (n=10) experiences when caring for delirious older people, describes how this experiences is of *Always being on guard*. These nurses encountered an unfamiliar person and, not trusting the older person, stayed at a distance to guard against unsafe acts towards them. These nurses doubted their own judgment and questioned their responsibility for the patient’s safety (Stenwall et al., 2007). Similarly, Agar et al.’s. (2012) interview based study with palliative, aged care and oncology nurses reports the theme *Management: maintaining dignity and minimizing chaos*. In this theme a need for constant nurse vigilance was described.
During delirium nurses are also concerned about the patient’s safety. In Schofield et al.’s (2012) study using discourse analysis, acute care nurses describe being influenced by the discourse of risk reduction and safety, constructing older people as risk objects. For these nurses care is reported to be Surveillance and Containment (Schofield et al., 2012). These findings suggest that nurses may encounter some dissonance between expectations for relationship or person oriented care and the need to provide safety oriented care. In Andersson, Hallberg and Edberg’s (2003) interview based study with orthopaedic nurses (n=48), the theme Patients being in a divided and/or different world describes how nurses interpreted their older patients’ behaviours as posing a threat or risk to themselves and, using a range of strategies, trying to bring them back to the nurses reality.

Lost Communication

During delirium it is hard for nurses to understand the older person’s reality and behaviour. Whilst Neville (2006) suggests that communication and other relational activities are important to older people during delirium, nurses describe caring for patients who perceive a different reality as frustrating and worrying. Nurses and their patients therefore became strangers (Bélanger & Ducharme, 2011). In Andersson et al.’s (1993) early non-participant observation study of an elderly women, nurses were observed providing care. These nurses talked to, rather than with, the older person. Conversations assumed that the patient was oriented to the nurse’s reality or orientating statements were used to emphasise the nurse’s reality. Nurses in this and a later study by Andersson et al.’s (2003) identified that they knew too little about the patient to make sense of their different world. In Andersson et al.’s (2003) later interview based study, orthopaedic nurses (n=48) described using a range of strategies to try to reach the patient in their different world and the older person as being out of their reach.

The findings of the studies in this section of the review support Hallberg’s (1999) and McDonnell and Timmin’s (2012) observations that it stands to reason health care staff find it demanding, challenging and a strain to care for patients during delirium; older people who are disorientated, perhaps agitated, experiencing illusions, hallucinations or have behaviours that may require restraint to maintain safety for the older person and others. Hallberg (1999) suggests that this may be a consequence of delirious patients often being located in hospital wards which have few or no trained psychiatric or geriatric staff to provide advice and support. When nurses find caring for patient’s burdensome their ability to interact with, involve and support family members during
delirium is likely to be impeded, possibly leading to family members being inappropriately involved in the older person’s care or having their needs and concerns left unknown and unmet.

**Nurses’ Perceptions of Family Members**

Delirium research at times also describes nurse perceptions of family member experiences and family involvement in care of the older person during delirium. In an Australian pilot participatory action research study Day, Higgins and Koch (2008, 2009a) explore nurse experiences during prevention, assessment and management of delirium in hospitalised older people. Hyperactive delirium and fear were described by these nurses as problems for all in the vicinity of the older person during delirium; nurses, other patients, their family and the patient themselves. The following nurse participant notices the fear experienced by family when confronted by hyperactive delirium in an unrelated patient.

> Recently one of the patients, a man, was going off. He’s yelling, he’s screaming. The family of another patient has come to warn us and said “we don’t know what to do, we’re afraid”. (Day, et al., 2009, p.252)

When care is demanding for health care staff and the presence of family is perceived to have a calming effect on the older person (Hallberg, 1999; Segatore & Adams, 2001), nurses may consider family members to be care resources. In Dahlke and Phinney’s (2008) interview based study involving registered nurses (n=12), strategies to *Buy time* away from the older person so that care can be provided to more acutely ill patients is described by nurses. Strategies that involved family members in care of the older person, such as sitting with the older person and providing assessment information, helped the nurses to do this (Dahlke & Phinney, 2008). Similarly Taiwanese nurses (n=4) in Lou and Dai’s (2002) pilot grounded theory study relied on family members to provide care and monitor the patient’s condition, though this finding may reflect normal cultural practices within Taiwanese families rather than nurse led family involvement in care.

The process of assessing and making a clinical judgement about the presence of delirium may include health care staff seeking information from family members. In Dahlke and Phinney’s (2008) interview based study registered nurses (n=12) working with older people in medical/surgical wards used an *Approach to care* that included “taking a quick look”. Nurses described time limitations for assessment of the older
person and when identifying that the older person’s cognitive status was “off”, seeking more information from others, including family members (Dahlke & Phinney, 2008). This was despite assessment tools, specifically the Confusion Assessment Method, being embedded in clinical assessment documents, revealing a possible preference for use of questioning and behavioural cues. The strength of asking family members for information was raised earlier by Fick and Foreman (2000) who explored recognition and management of delirium in hospitalised older people. In this study all interviewed family members (n=13) recognised an abrupt change in mental state in the older person, even though superimposed on pre-existing dementia. Profound differences in the level of consciousness and significant and abrupt changes in the usual mental state were noticed (Fick & Foreman, 2000). By encouraging family members to provide assessment information and report changes to the older person’s behaviour, health care staff can gain insight into the past health status of the older person as well as current delirium symptoms (Brown et al., 2007; Fick & Foreman, 2000; Walker, 2004).

Studies which specifically explore the feasibility or effectiveness of family participation in the care of hospitalised older people during delirium are scarce, making it difficult to make evidence based practice recommendations. One descriptive exploratory study involving family caregivers (n=15) of hospitalised older people explored the feasibility of family participation in prevention of delirium and reports that family involvement is feasible (Rosenbloom-Brunton et al., 2010). In this study family member implementation of five intervention protocols based on four baseline delirium risk factors were measured (Rosenbloom-Brunton et al., 2010). In addition, Black, Boore and Parahoo (2011), in a comparative time series study involving critically ill patients and their family (n=170; n=83 control and n=87 intervention) focused on the effect of nurse-facilitated family participation in the psychological care of the critically ill patient. Black et al. (2011) report that nurse facilitated family participation in the psychological care of critically ill patients did not significantly reduce the incidence of delirium but may enhance recovery. Whilst both studies acknowledge the importance of working in environments which support family-centred care, the interventions in both studies focus on reducing patient risk and using family members to enhance the therapeutic environment of the patient rather than the experience and support needs of family members themselves.

The discussion now moves to identifying and reviewing research into family member experiences during delirium. The perspective taken therefore shifts again; to that of the family member and what it is like to witness delirium and be with an older loved one at this time.
Family Members’ Experiences During Older Person Delirium

Before discussing family member experiences during delirium it is important to acknowledge that families vary enormously in their composition, and family member personalities, roles and relationships with the older person also vary. In addition, the characteristic changes associated with the presence of delirium, described previously and from a disease and illness perspective in Chapter 1: Study Introduction, suggest that the first encounter with a loved one during delirium is likely to be confronting and a shock. Perceptions of reality and social behavioural norms may be challenged, communication is likely to be disrupted, family dynamics may be strained and fears about mental health or loss of life may surface. Use of chemical or physical restraint may also affect perceptions of personal dignity and safety. These unexpected and unfamiliar experiences are likely to impact on family members and their coping. Despite this possibility the reviewed literature revealed only one Swedish qualitative study which specifically explored the lived experience of being a family member of an older person during delirium, one American quantitative study which investigated family member distress during delirium, one review and one discussion paper exploring literature related to delirium experiences, including experiences of family members (see Appendix A). Each of these is considered in the following sections, along with a comparison of family member experiences of delirium during older person care, palliative care and advanced cancer care.

Understanding the lived experience of close relatives encountering an older person during delirium was the aim of a Swedish study by Stenwall, Sandberg et al. (2008). In this study close relatives (n=10) to an older person were recruited from wards located in a metropolitan emergency hospital (n=2; 1=orthopaedic, 1=delirium management). These wards were described as often having older patients with delirium and staff as being experienced in documenting delirium as a condition. Close relatives were spouses (n=4) and adult children (n=6), most (n=9) indicating that they were born in Sweden. All patients (aged > 65 years) had received hospital care for delirium in the six months prior to the study. The relatives had visited the older person in hospital at least twice during the period of delirium. Though the study was guided by a descriptive phenomenological approach based on the work of Husserl (1970), Giorgi (1985), and Dahlberg, Drew, and Nystrom (2001), the researchers interviewed relatives on one occasion only and note that some difficulty was experienced by participants in recalling details of their experience. Interviews occurred during, or up to six months after relatives experienced delirium and were held at the relative’s home (n=5), on the ward.
(n=2), in a public place (n=2) or in a work office (n=1). Data analysis of transcribed interviews revealed the essential meaning of being a close relative who encountered an older person during delirium as *An encounter with a familiar person who has suddenly become unfamiliar* (Stenwall, Sandberg, et al., 2008). This essential meaning is further described through six constituents: *Change in the other person, Rapid and unexpected changes, Experiencing insecurity in the encounter, Trusting and mistrusting the other person, Experiencing loss and Experiencing exposure* (Stenwall, Sandberg, et al., 2008). For relatives in this study, the change in the older person during delirium was rapid and accompanied by feelings of shock, unreality and fear; relatives felt that every time they met the older person it was a new situation and they are unsure if they would encounter a familiar or unfamiliar person. There was a sense that the loved familiar person was lost and relatives were unsure if they would be able to reconnect with the person who is familiar. Relatives described being aware that the reality for the older person was not the same as their own, and trying to help by reaching the older person in their different reality. They also reported mixed feelings; trusting and mistrusting the older person. In addition, they experienced insecurity, loss, distress, unreality, fear, loneliness and being left to manage with their own limited knowledge. Stenwall, Sandberg et al. (2008) suggest that during this experience working to achieve mutual trust between the older person and relatives is an important nursing intervention.

In a quantitative adult day care study Bull (2011) investigated the extent to which the older person’s delirium symptoms were associated with coping and changes in family member (n=30) mental health. This study reports that 97% of family members did not know about delirium and attributed delirium symptoms to ageing. Median and mean delirium distress scores reflected relatively low distress levels and contrast with delirium related distress reported by Stenwall, Sandberg et al. (2008) and in palliative care/advanced cancer literature (Breitbart et al., 2002; Cohen & Pace, 2009). These lower scores may be influenced by family member attribution of delirium to normal ageing or reflect lower delirium severity in adult day centres compared to acute hospital wards. Also contrasting with Bull’s (2011) results, Agar (2012) reports that nurses perceive family members to be distressed when they don’t know the cause of their loved one’s delirium, witness their loved one when unsettled or not their usual self. In Agar’s (2012) interview based study set in palliative care, oncology and aged care, not being recognised by the person, a worsening situation and poor prognosis were sources of distress.
Family Members of Older People, Advanced Cancer and Palliative Care Patients

Included in this narrative review is research reporting delirium experiences for family members who are with loved ones when receiving palliative or advanced cancer care (see Appendix A). This approach reflects the experiences described by some women in this study and the varied contexts in which delirium is experienced by family members. It needs to be noted however, that though some care was designated palliative in this study, care was not delivered in palliative or specialist cancer care units as it was in the literature considered in the next section of the review.

Six qualitative (Canada n=2, Australia n=1, USA n=1, Japan n=1, England n=1) and five quantitative studies (USA n=3, Japan n=2) were identified which focused on the delirium experiences of family members of patients receiving advanced cancer or terminal care. In addition, one literature review was identified which included family member experiences of delirium during terminal illness. Patients included in these studies had a broad age range. In addition, it needs to be noted that not all older loved ones in this study were diagnosed as palliative. Therefore the results do not speak directly to the experiences shared by all family members in this study.

Family members of older people and palliative or advanced care patients report variations in their experience, though distress is reported across these contexts. For family members of older people mixed emotions are reported, based on feelings of trust and mistrust in their encounter with an older person who has become unfamiliar to them (Stenwall, Sandberg, et al., 2008). Facing an unfamiliar older person in each encounter is described as difficult and as creating feelings of insecurity, sadness, loss, vulnerability, fear, anger and distress (Stenwall, Sandberg, et al., 2008). Rogers & Gibson’s (2002) study describes how nurses perceived family members to be distressed and shocked or embarrassed by the behaviour of the delirious older person. Reactions of family members of patients with advanced cancer/receiving palliative care include feeling disturbed, anxious, distressed, guilty and worried about being with the patient (Braitman, 2003; Breitbart et al., 2002; Buss et al., 2007; 2009; Dumont et al., 2006; Namba et al., 2007). Neutral or positive reactions are also described and are linked to perceived relief for the patient from real suffering (Namba et al., 2007), perceptions that delirium is part of the normal dying process (Cohen & Pace, 2009; Namba et al., 2007), or expecting confusion because of heavy medication use during palliative care (Cohen & Pace, 2009). These findings suggest differences which possibly relate to varying family member perceptions of illness when different
diagnoses are known, when in different care contexts or when care is delivered using different care philosophies (e.g. palliative care and older person acute care).

In the following sections the findings of studies considering family member experiences of delirium in an older person and during palliative/advanced cancer care are discussed using the themes common to these studies: family member distress, rapid and unexpected changes, communication and loss, and exposure and knowledge. This discussion reveals what is common across these contexts as well as nuances to family member experiences.

**Family Member Distress**

In the study by Stenwall, Sandberg et al. (2008) family members described experiencing distress from facing a new and unfamiliar older person and not knowing if the person they knew will return, reflecting a focus on understanding family member experiences as an encounter between people and within relationships.

Advanced cancer studies highlight family member feelings of distress but also suggest that family member distress is more than that experienced by others in the health care team (Breitbart et al., 2002; Bruera et al., 2009). Results reported in an American questionnaire based study of hospitalised cancer patients and their family members by Breitbart et al. (2002) reports higher mean delirium-related distress levels for family members (n=75; mean 3.75, SD 0.47), than nurses (n=101; mean 3.09, SD 0.77), and patients themselves (n=54; mean 3.2, SD 1.1). Of interest is that predictors of nurse distress were different to those for family members. Variables significantly associated with family distress were severe physical decline, possibly occurring immediately before death (measured by Karnofsky Performance Status), presence of brain metastases and hyperactive delirium (Breitbart et al., 2002). For nurses the major predictors of distress were patient perceptual disturbances and severe delirium (Breitbart et al., 2002). These results were based on responses to a questionnaire with face validity, the Delirium Experience Questionnaire. This tool was developed by the researchers and contained only one question which asked family members to rate their level of distress on a numerical rating scale (zero to four). The validity and reliability of this questionnaire is therefore unknown. In addition, responses from family members were retrospective and relied on recall of distress after their experience and during the bereavement period. Sampling perceptions during this time may influence recall and alter reported distress levels. Bruera et al.’s. (2009) advanced cancer study used the same questionnaire and also reports median delirium distress scores that were higher for family members (n=99; median 3; 25-75% quartile 2-4), than patients (median 2;
25-75% quartile 0-3), and nurses/palliative care specialists (median 0; 25-75% quartile 0-1). The results of these studies suggest that nurse experiences may not be a sound basis upon which family member experiences can be understood nor make family support decisions. The reported high levels of family member distress points to the confronting nature of family member experiences during a loved one’s delirium and their need for sensitive support.

Palliative care studies also highlight family member feelings of distress when they are with their loved one during delirium. Questionnaire based research by Morita et al. (2004) and Morita et al. (2007) explored the distress experienced by bereaved family members when they encountered delirium symptoms in terminally ill patients during inpatient palliative care. In Morita et al.’s. (2007) most recent study (n=242), 32% of family members reported being very distressed (n=77; 95% CI: 22,38) and 22% distressed (n=53; 95% CI 17,28), with the presence of agitation a significant determinant of distress levels. In this study it is important to note that, for ethical reasons, 40 (6.7%) potential participants (n=600) were excluded due to profound emotional distress, potentially leading to under reporting of distress experienced by family members in the study. Morita et al.’s. (2004) earlier study also involved bereaved Japanese family members (n=195) and reports that all delirium-related symptoms, except somnolence, which occurred often or very often were perceived as distressing or very distressing in more than two thirds of family members. Results from this study are based on a researcher developed questionnaire which was described as having face validity from a pilot test involving 50 bereaved family members during the bereavement period. The results therefore also need to be considered with caution. The results reported in these studies do however support similar findings of family member distress reported by studies in advanced cancer care by Breitbart et al. (2002) and Bruera et al. (2009). The finding that somnolence was perceived as less distressing, and the potential for older people to display hypoactive delirium behaviours, raised the possibility that family members of older people may report different experiences to those described in advanced cancer and palliative care literature.

Further exploration of family member distress related to experiences of delirium is revealed in phenomenological studies from America and Japan. Cohen and Pace’s (2009) study of American caregivers (n=37; mean age 56 years; spouses, sisters, mothers and adult children) for patients with advanced cancer, reports that all caregivers had vivid memories of their delirium experiences and most described being distressed by the patient’s hallucinations and confusion. Not knowing the cause of
confusion was described as frightening. Though not specifically noted by other studies, Cohen and Pace (2009) describe caregiver concern about the meaning of confusion for the patient’s future as a source of distress. In this study the presence of delirium increased caregiver awareness that the patient’s death was imminent. However, some caregivers did not describe their experience as distressing, relating delirium instead to normal patient reactions and heavy use of medications (Cohen & Pace, 2009). In an earlier study of bereaved Japanese family members (n=20) to terminally ill patients, Namba et al. (2007) describes most family members as experiencing some distress from seeing the patient delirious in the last two weeks of life. This distress is attributed to seeing their loved one physically restrained and, like family members in Stenwall, Sandberg et al.’s. (2008) study, their loved one was changed from how they were before. In Greaves, Vojkovic, Nikoletti, White, and Yuen’s (2008) study experiencing delirium had a negative impact on caregivers. Feelings of anger, fear, hurt, sadness, isolation and embarrassment were described. Also described by caregivers was being fearful for their loved one and for themselves. When with their loved one in hospital they stayed with them overnight to compensate for lower levels of staffing and surveillance. They felt isolated when their loved one turned against them, especially when they were not like that with health care staff or other family members. Knowing other people saw how their loved one acted caused embarrassment (Greaves et al., 2008).

In addition to the studies reviewed so far the relationship between changes to mental health and caregiver perceptions of delirium was explored in one American study located in a palliative care setting (Buss et al., 2007). Buss et al.’s (2007) study used the Stressful Caregiving Response to Experiences of Dying (SCARED) questionnaire with caregivers (n=200). 19% of caregivers (n=38) for palliative patients were found to be far more likely to have generalised anxiety (OR=12.12; p<0.01) when they perceived the patient had delirium weekly or more often. In this study it is acknowledged that there are many possible causes for anxiety in this caregiver group, however the relationship between changes to mental health, specifically generalised anxiety, and frequently perceived delirium was shown to remain after adjustment for both caregiver burden (measured using the caregiver burden scale) and experience of other stressful events (OR=9.99; p=0.04). Although the number of caregivers with anxiety in this study was small (n=7) and the accuracy of caregiver diagnosis of delirium is unknown, the results raise the possibility that family members may develop changes to their mental health when, during palliative care, they experience their loved one in delirium.
Whilst based on different patient groups and in different countries, together the results of the studies reported here support Breitbart et al.'s (2002) initial study finding that many family members experience considerable emotional distress during experiences of a loved one's delirium. This research raised the possibility that family members would describe distress as a significant part of their experience, and pointed to their potential fragility and vulnerability as research participants.

**Rapid and Unexpected Changes**

Studies involving family members of older people and patients with advanced cancer/palliative care report observing changes in the patient which are characteristic of delirium (Cohen & Pace, 2009; Greaves et al., 2008; Namba et al., 2007; Stenwall, Sandberg, et al., 2008). Caregiver descriptions in a study reported by Cohen and Pace (2009), as described previously, were vivid and matched descriptions by patients themselves, however family members often provided more detail. Some caregivers in this study referred to the patient as “not crazy” or “not out of their mind” despite delirious behaviours. Observed changes were described by caregivers as being distressing, normal, expected or good, possibly illustrating caregivers’ understanding of the cause of the patient’s behaviour or disease progression (2009). Caregivers in a study reported by Greaves et al (2008), as described earlier, also described characteristics of delirium. Their most vivid descriptions related to their loved one’s verbal and physical aggression, for some oscillating between aggressive and peaceful. Also described were perceptual disturbances. Of interest is that one caregiver described her loved one’s withdrawal, possibly during hypoactive delirium, an experience less well described in the current qualitative literature. Family members of older people in Stenwall, Sandberg et al.’s. (2008) study, like those described above, described changes which reflect the characteristics of delirium as a disease, however their emphasis illustrates a focus on loss of the older person they knew and the rapid and unexpected nature of the changes they experienced rather than symptoms of a disease or condition.

**Communication and Loss**

Similar themes describing communication and loss are reported in studies focused on family members of older people during delirium and family members of palliative/advanced cancer patients. In a phenomenological study Brajtman (2003, 2005) explored the impact on family members (n=20) of terminal restlessness [delirium] and its management. Family members in this study were recruited through an Israeli
hospice after patient death and reports five main themes; *Multidimensionality of suffering*, *The need for communication*, *Feelings of ambivalence* and *The need for information*. In Brajtman’s (2003, 2005) study the theme *The need for communication* describes how family members of terminally ill patients have a need for communication with their loved one, particularly as death becomes imminent. However, when delirium is present the ability to communicate becomes compromised and family members in this study experienced frustration, anger and disappointment. In Brajtman’s (2003, 2005) study the use of medications to manage the patient’s symptoms lead to *Feelings of ambivalence* for family members. Family members are described as experiencing conflicting wants; wanting the patient’s suffering to be reduced but not wanting to lose access to their loved one (Brajtman, 2003). Cohen and Pace’s (2009) study reports *Concerns for the future* including fears that confusion would last till death and the chance to say goodbye would be lost. Caregivers in Greaves et al. (2008) interview based study describe changes to their loved one’s personality and ability communicate. For these caregivers their loved one was no longer the same person and they felt as though they had lost the person they knew. Unable to communicate, they lost the chance to say goodbye (Greaves et al., 2008). A similar aspect to family experiences is described by Stenwall, Sandberg et al. (2008). In this study communication during family member experiences is described by the constituent *Experiencing loss*. Family members describe losing contact with the known older person, fearing that delirium is a sign of approaching death and that they may never be able to make contact with the known older person again (Stenwall, Sandberg, et al., 2008). It is of interest that although loss is identified as part of family member experiences during older person delirium, a connection between this experience and theoretical understandings of loss has not yet been described in the literature.

**Exposure and Knowledge**

Existing family member knowledge and the need for information are described differently in the studies considered here. Brajtman’s (2003, 2005) palliative care studies and Cohen and Pace’s (2009) advanced cancer study suggest that information needs relate to patient symptom management. Most caregivers in Cohen and Pace’s (2009) study wanted to know the cause of their loved one’s confusion. For these caregivers not knowing the cause was frightening. Without information caregivers attributed confusion to pain or pain medications. Brajtman (2003, 2005) suggests information is also needed on the dying process and when the patient was expected to die. Stenwall, Sandberg et al.’s. (2008) study reveals that family members of older people experience exposure during their encounter with the older person. Having to
rly on their own knowledge, not knowing if their actions are correct, and being limited by their existing knowledge were experienced as difficult and tiring (Stenwall, Sandberg, et al., 2008).

**Limitations in Current Knowledge**

As noted in Chapter 1: Study Introduction, there is a vast literature on delirium as a medical condition in older people. This literature provides an extensive knowledge base about delirium prevention, identification, management and outcomes. However, the literature searched and considered in this review has revealed that there is less known about human subjective experiences of delirium; in particular, the meaning of experiencing older person delirium for family members. Hallberg (2002) argues that while health care staff need to know about recognition, causes and treatments for delirium in older people, they also need to know what it means to family members to have someone close to them have delirium, and what problems they face. Therefore a substantial gap exists in knowledge used to inform health care practice. This knowledge gap warranted attention based on the scarcity of research in this area, the prevalence of delirium and the potential for family members to experience being with their loved one during delirium, the distress that is likely to be experienced and the tendency for nurses to involve family members in care without understanding what their experience is like. Furthermore the single qualitative study identified in this review provides one description of family member experiences (Stenwall, Sandberg, et al., 2008), experiences which pertain to a specific group of relatives, their older family members, and their contexts. This one study is not sufficient to guide practice as we can never completely understand the experiences of others. As Benner (1994b) explains “human beings and worlds are not objects and cannot be frozen in time or explicated fully” (p. 100). Furthermore as older people with pre-existing dementia commonly have delirium (Flanagan & Fick, 2010) but were excluded in Stenwall, Sandberg et al.’s (2008) study, the experiences of this important family group were yet to be explored. In addition, older family members in Stenwall, Sandberg et al.’s (2008) study received care on two wards where delirium was a common and a well-documented condition among patients, one ward specialising in the care of patients with delirium. As described in Chapter 1: Study Introduction, older people with delirium are located across varied health care settings which are staffed by people with different levels of expertise, contexts which are not reflected in the one study reviewed. Although several investigations of family member experiences of delirium in palliative or advanced cancer are published, adopting these understandings for family members
in a different natural setting, with different situational attributes and where delirium is experienced by a different patient group is unlikely to adequately inform health care staff about the unique experiences and meanings for family members of older people. This literature does, however, provide insights which demonstrate the impact and importance of understanding family member experiences during their older loved one’s delirium.

The research question posed and addressed by this study helps to reduce the identified gap in our understanding. Situated within the many possibilities for further research, this study explored what it is like for family members in Australia to experience being with their older loved one during delirium. This study therefore considers a different natural setting to that currently reported in the literature, and without exclusion of loved ones with pre-existing dementia. Given Australian population ageing as well as the high prevalence of delirium in older people (see Chapter 1: Study Introduction), completing this research was considered timely for care of family members in Australia.

The next section of the review changes direction and considers literature which explores family member experiences of losing a loved one’s self during Alzheimer’s disease and related dementias (ADRD). While not considering experiences of delirium, these understandings were important to the study as many of the participants were with an older loved one who had delirium as well as pre-existing dementia. In addition, as data analysis progressed, losing a loved one’s self and the notion of absence emerged (see Chapter 5: Findings). As revealed by the following discussion this notion is also described by family members of older people with ADRDs.

Despite a recent change in dementia terminology in the DSM-5 (American Psychiatric Association, 2013), in the following sections ADRD and its related terms have been retained to provide continuity with the literature considered.

**Family Members’ Experiences: Older People and ADRD**

ADRD contrasts with delirium as it is a progressive and insidious clinical syndrome which primarily affects older people (World Health Organisation, 2006), as opposed to delirium which is an acute potentially reversible condition which develops rapidly (American Psychiatric Association, 2013). In ADRD the development of memory impairment along with at least one of the following cognitive disturbances, characterises the syndrome’s presence: aphasia, apraxia, agnosia, or a disturbance in executive functioning (American Psychiatric Association, 2000; Rogan & Lippa, 2002).
Although the effects of ADRD depend on the brain areas affected, the core and commonest symptom is progressive or incremental memory impairment (Wierenga & Bondi, 2011). Normally the decline in cognitive ability is protracted, progressing irreversibly over many years and to a sufficiently severe level that it impacts on everyday social or occupational functioning (American Psychiatric Association, 2000; Norman, Redfern, Briggs, & Askham, 2004; World Health Organisation, 2006). Different types of dementia have been described by the DSM (version IV-TR) distinguishing variants by their presumed aetiology (American Psychiatric Association, 2000). The commonest type of dementia in older people is Alzheimer’s disease (AD) (Raskind & Peskind, 2001; Small et al., 1997; Wierenga & Bondi, 2011). Other dementia types include vascular, substance induced persistent dementia and dementia occurring in association with other conditions such as head injury and Huntington’s disease (American Psychiatric Association, 2000).

Experiences of Losing a Loved One’s Self During ADRD

Family members or caregivers experience many losses when caring for a person with ADRD, and understanding these losses has been the focus of a substantial body of literature (Betts Adams, McClendon, & Smyth, 2008; Betts Adams & Sanders, 2004; Cohen & Eisdorfer, 1986; Loos & Bowd, 1997; Matthew, 1999; Meuser & Marwit, 2001; Moyle, 2002; Rycroft & Perlesz, 2001; Sanders, Morano, & Saltz Corley, 2002; Sanders, Ott, Kelber, & Noonan, 2008; Sanders & Saltz Corley, 2003). Clearly identified in this literature are family member experiences of losing a loved one’s self or personhood (Betts Adams et al., 2008; Collins, Liken, King, & Kokinakis, 1993; Moyle, 2002; Sweeting & Gilhooly, 1997).

To explore the notion of losing a familiar loved one during ADRD an electronic database search was completed using the search terms dementia, Alzheimer’s disease, loss, ambiguous loss, psychological absence, psychosocial death, social death, non-finite loss, identity loss, relative, carer, family member. To maximise search results Boolean logic, truncation and, where possible, database subject headings were used. Multiple search term combinations were employed and all searches were confined to English peer reviewed literature. The databases searched included the Cumulative Index to Nursing and Allied Health Literature, Proquest, Psychinfo, and Sociology Abstracts. Additional relevant literature was located by obtaining references cited in the retrieved literature and following clues and hunches.
The search process yielded 14 research reports which explored carer or family member experiences of losing a loved one’s self during ADRD, including one doctoral thesis. All but one study employed qualitative research methodologies for all or part of the study. In addition, 28 publications were identified of historical or theoretical relevance to the notion of losing a loved person’s self. No systematic reviews or meta-analysis were identified. The literature in this review has been updated to August 2013.

In the retrieved literature experiencing the loss of a loved person’s self often involved the perception of a progressive and profound change in the other person as an embodied self. This experience has been described using different terminology, including *mortification* (Goffman, 1961), *phenomenological death* (Kastenbaum, 1969), *malignant social psychology* (Kitwood, 1997), *social death* (Sudnow, 1967; Sweeting & Gilhooly, 1991-92, 1997), *psychosocial death* (Doka & Aber, 1989), *ambiguous loss* (Boss, 1999, 2004; Boss & Greenberg, 1984), *psychological absence* (Boss, 1999, 2006) and *non-finite loss* (Bruce & Schultz, 2001). Together these terms reveal that loss cannot be defined solely on a physical or biological basis. Rather, Shabad (1989) argues that we can experience other losses when a person remains physically present. To maintain clarity in the following discussion *losing a loved one’s self* is used unless a more specific term is needed for discussion clarity.

Identified across the retrieved literature are family member or carer experiences of losing a loved one’s self during a loved one’s ADRD, from early studies in 1989 (Doka, 1989b; Fontana & Smith, 1989), to more recent research by Gillies (2011). An early small grounded theory study by Orona (1990) explored carer (n=5) experiences of identity loss in a loved one across different stages of dementia. In this study carers experienced the loss of their loved one’s identity to the point where they became unrecognisable. These carers lived with daily reminders of their loss and struggled to maintain signs of the person they knew from the past. Collins et al.’s. (1993) telephone interview and questionnaire based study explored loss and grief in a larger mixed group of carers (n=82; spouses=57, adult children=14, siblings or other relatives=11). Like Orona’s (1990) study, Collins et al.’s (1993) study reports carer awareness of losing the known person long before their biological death. Of the six reported themes *Loss of familiarity and intimacy* describes the carer’s awareness that the person they knew had gone before their death. Data in this study was collected after their loved one’s death (average 14 months), possibly when carers were still grieving, potentially influencing carer perceptions and accounts and accentuating or diminishing their reports of loss. Later, in a large interview based study Sweeting and Gilhooly (1997) explored the phenomenon of social death for a mixed group of family carers (n=100;
spouses=50, mothers=35, fathers=9, siblings=3 and mother’s-in-law=3) to loved ones in different stages of dementia. In this study over a third of the participants described both beliefs and behaviours suggestive of their loved one’s social death before biological death. More recently in a large cross sectional study Betts Adams, McClendon, & Smyth (2008) explored personal and relational losses and changes in relationship quality for carers of family members with dementia. These caregivers (n=428) were mostly spouses (72.9%) and almost two thirds were female (64.3%). In this study a loss of intimate exchange included a loss of the person the caregiver used to know (Betts Adams et al., 2008).

**Caregiver Roles and Relationships**

While there are several studies exploring family or carer experiences of losing a loved one’s self during ADRD, there has not been a systematic exploration of experiences for different carers or family members; for example male spouses, adult sons or adult daughters. In the retrieved literature there were only a few studies that differentiated by role or relationship. Most were small studies and, where more than one study was identified, other factors were dissimilar (e.g. gender, the stage of ADRD or living arrangements of the person with ADRD).

Studies considering different carer types included a recent and small study based on interpretive phenomenological analysis. In this study O'Shaughnessy, Lee and Lintern (2010) explored the experiences of home based spousal carers (n=7; 5 wives and 2 husbands) and the impact of their partners’ cognitive decline on their couple relationship. The participant’s partners had middle stage dementia and had been diagnosed with dementia for over two years. Based on analysis and interpretation of semi-structured interview data, O'Shaughnessy et al. (2010) describe four overarching themes, including *Connectedness and separateness*. This theme describes how spouses had a concurrent sense of relationship connectedness and increased sense of separateness. With the loss of the person who was their spouse, the attachment relationship had changed from equal partners to increasing dependency (O'Shaughnessy et al., 2010). In an American study Sanders, Morana and Saltz Corley (2002) used open ended questions at the end of a survey in a larger study to explore the experience of loss and grief for male carers (n=71; 43 husbands, 21 sons, 7 other relationships). In this study all male carers expressed loss. Many of the losses the participants described related to the perception of their partner’s identity. In the non-grieving participant group (32%; n=23), one of the two themes which emerged from analysis of open question survey responses was *Emotional disassociation from the*
care recipient. Described in this theme are participant experiences of their loved one as dead, a stranger or an old man they didn’t know. A sense of loss about the changes in their loved one is reported (Sanders et al., 2002). As this study included both sons and husbands, the different relationships of these male carers with their loved one may have influenced their experiences of loss. Other factors may have been different gender relationships with the care recipient as only 73% were women, or the influence of different care settings, including home, assisted living and residential aged care.

In an earlier small study of husbands caring at home for their wives, Matthew (1999) used open ended interview questions to explore loss experiences of husbands (n=6) and to explore if these experiences were like bereavement. In this study fourteen categories of emotional experience are reported. The first category, *Husband’s perceptions of their wives as they were prior to the onset of dementia*, describes how husbands noticed losing their wife, making comparisons with the past and present person and accepting the loss of the person they know (Matthew, 1999). Dupuis’ (2002) more recent Canadian study specifically focused on the experiences of adult children and accessed a larger participant sample (n=61). Using in-depth interviews Dupuis (2002) explored daughter (n=38) and son (n=23) experiences of ambiguous loss when their loved one has dementia and resided in a long term care facility. Using a grounded theory approach, Dupuis (2002) adds to the concept of ambiguous loss by reporting changes to the ambiguity carers experience through the phases of loss in dementia. The phases identified were *Anticipatory loss, Progressive loss* and *Acknowledged loss*. Psychosocial death is reported as an *Anticipatory loss* in the early phase of dementia, moving to a fluctuating loss in the *Progressive phase* and a permanent loss in the *Acknowledged phase*. Importantly this study suggests that absence has a dynamic quality, a quality unarticulated in other reported research (Dupuis, 2002). Though the studies of different carer type are few, they provide evidence that spouses and adult children experience losing a loved one’s self during ADRD. This evidence is, however, insufficient to draw conclusions about the similarities and differences for specific carer relationships and genders.

**Care Contexts**

Exploration of carer experiences of losing a loved one’s self during ADRD have included a range of care settings, though most studies include only small participant numbers and there a few replication studies. Some studies focus on home based caring locations, others day centres and others on residential care services. More
common are studies that recruit carers or family members with loved ones located across multiple care settings.

In an early study, Fontana and Smith (1989) accessed a day centre with an average daily population of fifty patients with Alzheimer’s disease and, using non-participant observation, explored the importance of routinized practices for the maintenance of self. This study describes how the self of the person with dementia slowly unravels and Unbecomes, becoming unrecognisable and empty of the familiar person. Witnessing the other person and their unbecoming is described as creating feelings of emptiness in the caregiver’s hearts. When elements that form the backbone of the self-wane, it is argued that the performance of social routines allows the self to continue to exist in the eyes of others. Maintaining social routines is therefore suggested as a way to create and maintain a sense that the other’s self remains (Fontana & Smith, 1989).

Gillies (2011) reports on an interview component to a large mixed methods study. In the interview component co-resident carer (n=20, spouses n=15) experiences of dementia were explored. From an interview (n=37) analysis schema derived from grounded theory Gillies (2011) reports seven themes describing experiences along a trajectory of continuity and loss. The theme Continuity and loss: identifying continuity describes caregiver experiences of losing their loved one as a recognised and familiar self. Described is a range of experiences from minimal change to almost complete loss of their loved one’s former identity. The theme Continuity and loss: managing the experience describes how carers seek to minimise the erosion of their loved one’s previous self and attempt to find continuity with the person they know. The carers try to preserve their loved one’s recognised and familiar identity and facilitate continuation as the same person. The theme Continuity and loss: losing, loss and caring despair, and The language of loss and losing describes carer language which signals an end of being and the degree of loss they were experiencing. Carer terms such as “stranger”, “lost”, “going”, “finished”, “shrinking”, “away” and “different” describe the extent of the carers perceived loss (Gillies, 2011).

In an Australian study, Moyle (2002) explored carer (n=15) experiences of living with loss when caring for a family member with advanced dementia in a long term dementia unit. Following content analysis of focus group data the major theme reported was Living with loss. Of the 6 reported sub-themes, Loss of personhood describes the participant’s need to keep their family member as they remembered them. Participants perceived their family member was dead as they no longer resembled the known person. The loss of the other’s self was such that the sub-theme Losses-the
anticipation of death describes how the participants longed for the stress of living with their loss to be relieved by their family member’s death (Moyle, 2002). These retrieved studies, along with those that have mixed care settings, suggest that carers experience the loss of a loved one’s self across care settings, from home to residential care, however no generalisations can be made without further research evidence. It is possible that care location influences perception of a loved one’s presence, perhaps through the amount of time spent together or constraints felt in various contexts. It is also possible that the stage or progression of a loved one’s ADRD will influence care setting and so influence carer experiences of losing a loved one’s self.

Progression of ADRD and Losing a Loved One’s Self

Most of the studies in the literature considered included loved ones with unspecified or mixed stages of ADRD, making it difficult to generalise about the loss experience of carers as the condition progresses. Only one study by Moyle (2002) focused on carer experiences of loss when a loved one was in an advanced stage of dementia and another by Betts Adams and Sanders (2004) considered loved ones with early, middle and late dementia stages. Moyle (2002), as previously described, reports that the losses incurred by carers continues despite their loved one being placed into residential care setting, including the loss of their loved one’s self, and that care practices in residential care settings can make it more difficult for carers to keep their loved one as they remembered them. Betts Adams and Sanders (2004) adopted a mixed method approach to explore differences in carer (n=99) losses when looking after people in early (n=24), middle (n=41) and late (n=33) stages of dementia. It is of interest in this study that carers with loved ones in different stages of dementia described different losses. In the late stage dementia group carers reported thinking about the loss of the characteristics of their love one whereas carers with a loved one in the early stage reported noticing changes in communication and loss of shared activities. Carers in the middle group reported threats to their own health and their own losses, for example loss of freedom and socialisation. Also of interest is that this study suggests spouses were more susceptible to perceiving a loss of self than other relatives (Betts Adams & Sanders, 2004). Based on feeling as though the loved one is already gone in the late stages of dementia, carer losses in the late stage are equated to losses after the death of a loved one. The researchers suggest that it is important to acknowledge the particular carer losses in each stage and to facilitate stage relevant grieving (Betts Adams & Sanders, 2004).
In addition to studies which focus solely on ADRD, Gillies and Johnston (2004) used qualitative interviews from two studies to compare the loss experiences of carers (n=20) to dementia patients with carers (n=14) to people with advanced terminal cancer. Gillies and Johnston (2004) report the themes Loss of role, Maintaining or preserving identity, Carer’s perception of loss of personhood, Impact of care provision on identity maintenance and Carer maintenance of former self. Through these themes a common experience between the two carer groups is identified. Both groups of carers speak of their loved one as an object or a problem to be sorted out and attempt to facilitate continuation of their former loved one’s self. Gillies and Johnston (2004) suggest that dementia, like advanced terminal cancer, presents a fundamental challenge to maintaining a sense of self for the person and for family members over time. Carers routinely describe a change in the person’s identity, at times a change that makes them beyond recognition. Both can progressively and often irreversibly affect the person’s memory, thinking, judgement, orientation, language, behaviour, personality and physical wellbeing (Gillies & Johnston, 2004). The possibility of carer experiences of losing a loved one’s self being common to different conditions that progressively and often irreversibly affect the family member’s self is of interest to the study of delirium reported in this thesis.

As a whole the retrieved literature on losing a loved one’s self during ADRD varies in methodology, design and research question. However, there is sufficient evidence to suggest that carers often experience losing a loved one’s self during ADRD. During ADRD they experience the person as changing in familiarity insidiously and irreversibly over time, their image of the person shifting as these changes happen (Chan, Livingston, Jones, & Sampson, 2013; Piiparinen & Whitlatch, 2011). Referred variously over time by carers and family members as the slow extinction of their personality (Aronson & Lipkowitz, 1981), the long goodbye (Matthew, 1999), the deselling of Alzheimer’s disease (Tobin, 1999), goodbye without leaving (Boss, 1999), loss of self (Cohen & Eisdorfer, 2001), living death (Gillies & Johnston, 2004), and receding known self (Piiparinen & Whitlatch, 2011), what family members experience is a loss unrelated to biological death; one where what is lost is the person’s self rather than their corporeal presence (Gillies, 2011). The most painful aspects of ADRD for family members or carers is watching their loved one’s progressive deterioration and psychological loss (Dupuis, 1997; Dupuis, 2002). For family members there is little they can do to reverse the changes ADRD brings (Piiparinen & Whitlatch, 2011). Witnessing the slow extinction of their loved one as a person may be more emotionally traumatic.
than witnessing their biological death, and life may seem like a funeral that never ends (Aronson & Lipkowitz, 1981). The experience of living with a lost self and a change of identity leads to the person with ADRD being viewed as different and as having otherness (Naue & Kroll, 2009). For family members this type of loss leaves their loved one’s corporeal presence in the world empty of substance (Gillies & Johnston, 2004), and is connected to carer/family member experiences of grief prior to and after their loved one’s biological death (Holley & Mast, 2009).

To further understand the meaning of losing a loved one’s self for family members, literature specific to theoretical understandings of this notion have also been considered in this review. Much of this theory has been developed from research into family member experiences during ADRD and other long term, often progressive conditions or situations, with no specific mention of family member experiences of losing a loved one’s self during delirium. Although this theoretical material also discusses the relationship between losing a loved one’s self and complicated grief and mourning, particularly anticipatory mourning and disenfranchised grief (Chan et al., 2013; Doka, 2010; Doka & Aber, 1989; Holley & Mast, 2009; Rando, 1986b; Walker, Pomeroy, McNeil, & Franklin, 1995), these notions of mourning and grief are only briefly considered in following review and only as they relate to the concepts for losing a loved one’s self within non-life threatening illnesses. This decision was informed by the analysis of the women’s experiences in this study, an analysis which was unclear about the women’s grief and mourning during their older loved one’s delirium. It is possible that this lack of clarity relates to the rapid onset of delirium and its varied resolution for the women who shared their experiences. Clarifying the experience of mourning and grief could, however, be a valuable area for future research, particularly for understanding family member experiences during persistent and recurring delirium (see Chapter 7: Discussion and Conclusions).

**Theoretical Understandings: Loss of a Loved One’s Self**

Evident in the literature are theoretical understandings of non-death losses such as losing a loved one’s self (Boss, 2006; Bruce & Schultz, 2001). These understandings are thought to have developed from early seminal work by Lindemann (1944) on the symptomology and management of grief, particularly anticipatory grief, Bowlby’s (cited in Holmes, 1993) work on attachment theory, and Engel’s (1964) work on grief as a response to non-death losses (e.g. loss of a cherished object, an ideal or body part). Other significant contributions to understanding non-death loss and their grief reactions have been made by Doka and colleagues (Doka, 1997, 2000, 2004, 2010, 1989b;
Doka & Aber, 1989; Doka & Davidson, 1997) who considers psychosocial death and disenfranchised grief, Rando and colleagues (Rando, 1997, 2000a, 1986b) who consider loss and anticipatory mourning/grief, Boss and colleagues (Boss, 1999, 2004, 2006; Boss, Caron, & Horbal, 1988; Boss, Caron, Horbal, & Mortimer, 1990; Boss & Greenberg, 1984) who consider ambiguous loss and, more recently, Bruce and Shultz’s (2001, 2002) consideration of non-finite loss. This knowledge base has altered the commonly accepted notion that social death follows biological death, and now better reflects the complex and highly varied nature of human loss, grief and mourning. Of particular interest to this study is the argument that losing a loved one’s self can occur before biological death in circumstances related to changes in health status (Boss, 2006; Doka & Aber, 1989). This type of loss has been described previously through discussion of family member experiences during their older loved one’s ADRD.

Theoretical literature which considers the loss of the familiar self also describes what it is that leads family members and carers to perceive their loved one as no longer present. Boss (2006) suggests that this type of loss centres on what makes a person who they are to other people, and what enables other people to perceive that they share the world with a recognisable self (Boss, 2006). Research and theoretical debate reveals differing views however, often reflecting different concerns and background theoretical frameworks. Working with people who have ADRD, Kitwood (1998) argues that a person’s identity, self or personhood is more than cognitive abilities or associated characteristics, and considers personhood to be a standing or status bestowed on one person by another, implying recognition, respect and trust. Orona (1990) argues that people come to know aspects of one another through countless daily interactions and, as time passes, the development of mutual knowledge of everyday gestures, nuances, and idiosyncrasies that disclose who the other is and who I perceive them to be. Harrison (1993), taking a social view, suggests that personhood is defined by feelings, sensations, emotive responses and the ability to live relationships characterised by interrelatedness and interconnectedness. Crisp (1999) argues that the experience of another’s personhood is influenced by our attitudes towards their illness, in Crisp’s (1999) case dementia, but also by our underlying attitudes and beliefs about what constitutes personhood and the capabilities and qualities we deem to be essential to it. In Crisp’s (1999) view people tend to see the self as an inner essence or a given set of qualities and characteristics that we think make up a person’s true identity. As a personal endowment, Crisp (1999) argues the inner essence is something we hope to keep throughout life but, in changed circumstances, may be altered and become stunted, hidden or lost. Charmaz (1997)
discusses identity dilemmas posed by chronic illness and how men attempt to recapture a past self in order have a congruent current self. This implies the need to maintain "essential qualities, attributes, and identities of this past self" (Charmaz, 1997, p. 49) in order for the same self to be perceived in the present. Sweeting and Gilhooly (1991-92) and, more recently Kitwood (1997, 1998), argue that ceasing to recognise another person as having characteristics of a recognisable identity or self, places the person at risk of being treated in disrespectful, depersonalising and dehumanising ways. Perceiving a person as still endowed with their true self is thus influenced by assumptions about what constitutes self. Losing another person's self stems from perceiving another person's valued attributes, physical functions and social roles as missing.

**Conceptualisations of Losing a Loved One's Self: Absence and Loss**

In the following sections concepts used to describe the notion of losing a loved one's self during changes in health are discussed, along with their relationship to grief and mourning.

*Non-finite Loss*

At the broadest conceptual level, Bruce and Shultz (2001) include experiences of losing a loved one's self, or their psychological presence, within their conceptualisation of *non-finite loss*. Defined within a sociological and psychological framework, non-finite loss refers to "enduring loss precipitated by a negative life event or episode that usually retains a physical presence, a psychological presence or both" (Bruce & Schultz, 2002, p. 9). In addition to intellectual or other developmental disabilities, the life situations considered by Bruce and Schultz (2001) to involve non-finite loss include relationship breakdowns, disappearance of a family member, infertility, traumatic injury and progressive or degenerative illness (e.g. dementia). These conditions reflect the enduring nature of non-finite loss. Unlike abrupt losses associated with biological death, non-finite losses become more evident with the passage of time, have no clearly marked conclusion and do not occur in relation to biological death (Schultz & Bruce, 2005). Acting as a relentless and irreversible threat to people's hopes, wishes, ideals and expectations, non-finite loss generates a sense of disconnection and immerses families in grief (Bruce & Schultz, 2001; Schultz & Bruce, 2005). In Bruce and Shultz's (2001) view non-finite loss disrupts a person's sense of balance as absence threatens assumptions about the world.
**Ambiguous Loss**

The concept of *ambiguous loss* was introduced by Boss (1999) in the mid 1970’s. This type of loss is described as an unclear or incomplete loss of a person that defies closure and creates ambiguity and confusion for family members. Important to this discussion is Boss’s (1999, 2006) description of two specific sub-types of ambiguous loss, based on physical and psychological absence or presence. Both have similarities with the loss described more recently by Bruce and Shultz (2001).

The first type of ambiguous loss occurs when family members perceive a loved one to be physically absent but psychologically present, often because it is unclear if the person is physically dead or alive (Boss, 2006). This category reflects research and involvement with families traumatised by war, terrorism, or natural disasters, and includes when a family member is missing in action or a child goes missing (Boss, 1999, 2006).

The second, and more relevant type of ambiguous loss for this study, is termed *psychological absence* (Boss, 2006). This type of loss refers to when family members perceive a loved one to be physically present but emotionally or cognitively absent (Boss, 2006). Drawn from earlier work by Feigelson (1993), and Boss’ (2006) understanding of the psychological family unit, psychological absence is a change from the everyday and taken for granted way someone is in life, to a bizarrely distorted and profoundly altered known person. Boss (2006) argues that this type of loss has existential significance as it questions reality and how alive and embodied a person is. As a consequence of this loss individual roles and status become confused and family members no longer know what to do or say (Boss, 2006). Common situations considered by Boss (2006) to be characterised by psychological absence include divorce, remarriage, homesickness, adoption, preoccupation with work, and obsession with leisure activities (e.g. television and internet games). Other situations include chronic mental illness, coma and brain injury (Boss, 2006). With a focus on the ambiguity of loss, Boss’s (2006) *psychological absence* is one concept that has aided understanding of carer loss and grief during a loved one’s ADRD.

Boss’s (1999) umbrella concept of ambiguous loss is concerned with the uncertainty of family membership boundaries when family members cannot determine who is in and who is out of the family system (Boss et al., 1988). The loved one family members are expecting is out of reach physically, cognitively or emotionally (Boss, 2006), and they can never be sure if their loved one is absent or present, dead or alive, or coming back (Boss, 1999). The loss creates confusion for family members about their roles and
status within their relationships, as well as creating guilt about experiencing feelings of grief (Boss, 1999).

As a relational disorder, ambiguous loss defies resolution because there is no external certification (e.g. death certificate), or other social markers (e.g. a funeral and mourning rituals to say goodbye are not held), that confirm the loss exists, making it difficult for the family to be sure that their loss is real (Boss, 2006). Though the loss feels real, its ambiguity makes it difficult for the family to be sure and difficult for them to communicate to others. According to Boss (1999, 2006), those who experience ambiguous loss have to deal with a loss that is not clear-cut nor as well understood by other people as losses from biological death. As a consequence, family member experiences of ambiguous loss may be missed by others (Boss, 2006), including health care staff.

The core issues for family members during ambiguous loss are that the loss cannot be resolved, there is ongoing ambiguity and there is the never ending stress and pain of living in limbo (Boss, 2006). Though the loss of a loved one creates distress and trauma universally across all cultures and religions, Boss (2006) argues that experiencing ambiguous loss is often highly traumatic because the distress of ambiguity, the pain of un-resolvability and chronicity are experienced together with the universal pain of loss. Not being able to control or clarify the loss creates so much ambiguity that family members experience chronic pain, confusion, shock and distress (Boss, 2006). When their loved one’s mind and/or body is missing, closure cannot be achieved and their pain persists. Like Post Traumatic Stress Disorder and critical incidents, ambiguous loss has origins in trauma and stress but is neither of these conditions (Boss, 2006). Because reciprocal relationships and a clear identity are lost, Boss (2006) argues that psychological absence distresses family members no matter how healthy or resilient. However, Boss (2006) also acknowledges that, though distressing, ambiguous loss does not have to be problematic for family members. Though testing family resilience, ambiguous loss is mainly a problem when family members experience feelings of hopelessness that lead to depression and passivity, and feelings of ambivalence that lead to guilt, immobilisation and anxiety (Boss, 2006). Boss (2006) remains optimistic that family members do and can live well though experiencing ambiguous loss.

**Psychosocial Death**

Doka and Aber (1989, 2002) consider *psychosocial death* to be when “the psychological essence, individual personality, or self is perceived as dead, though the
person physically remains alive” (Doka & Aber, 1989, p. 189), highlighting the significant impact a change in essence or personality makes in the perception of other people as familiar (Doka & Aber, 1989). Doka and Aber (1989, 2002) argue that those attached and committed to the other person, such as family members, notice when the qualities of the other person are changed, perceiving them as no longer present as before. Like Boss (1999, 2006), Doka and Aber (1989) relate psychosocial death to the loss family members perceive in association with mental illness and chronic brain syndromes, such as ADRD.

Of particular interest for this study is Doka and Aber’s (1989) view that the underlying condition causing psychosocial death can be viewed on a continuum of reversibility, with each point along the continuum raising different issues and difficulties for grieving. In reversible conditions Doka and Aber (1989) maintain there is sustained hope for recovery, reconciliation and resolution, but argue that this may be tempered by impatience with a slow recovery or anger at the person. Unlike later works, such as that noted earlier by Bruce and Shultz (2001) and Boss (2006), Doka and Aber (1989) argue that psychosocial death can be a reversible rather than an evolutionary loss. With irreversible conditions such as dementia, Doka and Aber (1989) maintain that though this knowledge may be resisted or denied, the loss is certain and there will often be a sense of helplessness. They argue that family members of patients with ADRD grow to accept the fact that decline is inevitable, irreversible and thus beyond their control. In addition, Doka (2000) suggests that, similar to Sartre’s (1943/2003) notion of partial lack, psychosocial absence can be perceived as partial or total by other people. These extra dimensions take into consideration fluctuations in perception of another person’s self; perceptions which oscillate between normal/present and unfamiliar/absent, perhaps in response to changes in health.

Doka and Aber (1989, 2002) suggest that people who experience the psychosocial death of a loved one, also experience loss and grief. The degree to which this loss is experienced depends on factors such as the person’s level of change or disability, and the degree to which knowledge of the change is shared and perceived by others (Doka & Aber, 1989). Keeping the condition secret may cause additional stress and burden, however open acknowledgement may cause additional stress from stigma and censure. Grief arising from the experience of psychosocial death is convoluted and difficult to resolve because liberation from ties to the person cannot occur easily when the person remains alive and present in the immediate environment (Doka & Aber, 1989). Though grief is often held in a suspended state Doka and Aber (1989) suggest
that this state protects the person and the loved one from the detrimental distancing effects of pre-mature resolution of the loss.

Early Concepts

In the 1960s the concept of psychological death (Kalish, 1966; 1968) was used to describe when a person ceased to be aware of their own self; when consciousness was perceived to be dead and the person did not know who they were. The concept of mortification also appeared in the literature in the 1960s in relation to the dispossessing and non-person treatment of people living in institutions (Goffman, 1961). Social death has also been used to refer to when people, who once knew an individual as alive, now considered them to be dead or non-existent, behaving as though the individual has ceased to exist (Sudnow, 1967). Attention was drawn to social death when American studies described “non-person” treatment styles used by hospital staff when caring for comatose patients (Glaser & Strauss, 2005/1965; Sudnow, 1967). In studies involving carers of people with dementia, Sweeting and Gilhooly (1991-92, 1997) observed that some carers behaved as though their loved one was already dead, speaking of how the person was already gone and how they cared for a shell. Sweeting and Gilhooly (1991-92, 1997) argue that social death occurs in ADRD, stemming from the unique coalescence of a lengthy fatal disease, old age and the resulting loss of a recognisable identity or personhood. Similarly, Kitwood (1990; 1997, 1998) has used the notion of malignant social psychology to conceptualise the ways people have depersonalised, invalidated and treated as dysfunctional older people with dementia. In contrast, Kastenbaum (1969, 1977) used the concept of phenomenological death as a subtype of the wider term psychological death. In this conceptualisation it is argued that a person can lose the qualities by which they are known, either temporarily or permanently, and that phenomenological death occurs when a non-dead person gives no real indication that the known person continues to exist inside the body. For Kastenbaum (1969, 1977) a significant aspect of being a person is being perceived as that person by others.

Grief and Mourning

There is considerable evidence to support the argument that family members who experience a sustained change in a loved one’s self, endure a deep personal loss and complicated grief reactions (Boss, 1999, 2004, 2006; Bruce & Schultz, 2001; Doka, 1987, 2010, 1989b; Doka & Aber, 1989; Rando, 1986b). When we grieve, Bruce and Shultz (2001) suggest that an ideal, or the world that could have been, is grieved. Boss
argues that experiencing ambiguous loss is inherently highly traumatic because the distress of ambiguity and the pain of “un-resolvability” are experienced together with the universal pain of loss. Perceiving a loved one as gone when they are physically present can make family members feel helpless (Boss, 1999). Finding closure is difficult with ordinary losses, however Boss (2006) and Doka and Aber (1989) argue accepting the psychological loss is more difficult as the person’s continued daily presence in life denies the reality of the loss, and because the loss is rarely recognised by others as real. In Doka and Aber’s (1989) view the nature of the situation complicates emotional responses for family members, creating ambivalence, anger and guilt, at times isolating them from valuable support mechanisms (Doka & Aber, 1989). These theoretical descriptions suggest that grief from the loss of the familiar person is likely to be painful and may be complicated (Boss, 2006); that family members may experience anticipatory mourning when the loved one is dying (Doka, 2000; Rando, 2000c), or disenfranchised grief when losses are unsanctioned and hidden (Bruce & Schultz, 2001; Doka & Aber, 1989).

Disenfranchised Grief

Doka (1989a) defines disenfranchised grief as “grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publically mourned or socially supported” (p. 4). In his view these losses are not appreciated by other people in the family member’s situation (Doka, 2002b); other people are simply unable to understand the family member’s loss and may fail to validate and support the family member’s expressions of grief (Doka, 1989a, 2002b). In Doka’s (1989a) view the loss experienced in response to a loved one’s psychosocial absence is a paradox; creating different grief reactions and particular difficulties for those experiencing this type of loss and, at the same time, isolating them from sources of support because their grief is suppressed. According to Doka (1989a) disenfranchising grief exacerbates mourning by intensifying and complicating normal grief emotions and yet many of the factors that facilitate the normal expression of grief are not present (e.g. confirmation of death, funeral rituals and or opportunities to participate in caring). As social support is marginalised, family members find it hard to assert their right to mourn and their grief remains private (Doka, 1999); suppressed and often suspended. In addition, family members may not be able to acknowledge the loss themselves, so adding to their inability to grieve. This later dimension of disenfranchised grief is referred to by Kauffman (1989) as self-disenfranchisement; where shame or embarrassment about the views of other people in the person’s world impedes self-acknowledgement of loss.
The concept of disenfranchised grief is grounded in the idea of societal norms which specify who and when people should grieve (Doka, 2002b). Different reasons are proposed as origins for disenfranchised grief, reflecting societal norms, the felt sense of loss, and peoples different attachments to one another (Doka, 1999). These reasons include having a relationship with the person who is not socially recognised, a lack of societal recognition of the loss itself or the significance of the loss, and being a griever who is perceived to be unable to grieve (Doka, 1989a). In relation the women’s experiences in this study a lack of health care staff recognition of their loss and not perceiving their loss as significant were important situational factors.

**Anticipatory Grief and Mourning**

Since first introduced by Lindemmean (1944), the concept of anticipatory grief has received considerable attention in the literature. Much of this attention has been on the development of the concept by Rando (1986a, 1997, 2000a, 2000b, 2000c, 1986b). The primary focus of anticipatory grief was initially on reactions to the threat of death or separation (Lindemann, 1944) rather than responses after biological death. Importantly anticipatory grief was also not simply considered to be post-death grief commenced before the death of a loved one, so extinguishing parts of grief that would normally be experienced after the loved one’s biological death (Rando, 1986b). However, in recent times Rando (2000b) has renamed anticipatory grief to be anticipatory mourning. This new terminology considers grief to be the reaction of a person to the perception of loss, and mourning as including grief and progressing to actions taken to cope with, adapt and accommodate the loss and its consequences. Rando (2000b) has defined anticipatory mourning as:

The phenomenon encompassing seven generic operations (grief and mourning, coping, interaction, psychosocial reorganisation, planning, balancing conflicting demands, and facilitating an appropriate death) that, within a context of adaptational demands caused by experiences of loss and trauma, is stimulated in response to the awareness of life-threatening or terminal illness in oneself or a significant other and the recognition of associated losses in the past, present and future. (p. 4)

The concept of anticipatory grief/mourning has been applied in situations where family members are caring for older loved ones with dementia. However, as one of the parameters for this concept is an awareness of life-threatening or terminal illness in
another person (Rando, 2000b, p. 4), it’s applicability to the women’s experiences in this study is potentially specific to some women; those who were with loved ones when terminally ill and in delirium.

The theoretical literature considered here has focused on the loss of a loved one’s self. The discussion has described what it is that leads family members and carers to perceive their loved one’s self as absent; no longer present. Current literature reveals several concepts which relate to and describe the notion of losing a loved one’s self including psychosocial death (Doka & Aber, 1989), ambiguous loss (Boss, 1999, 2004; Boss & Greenberg, 1984), psychological absence (Boss, 1999, 2006) and non-finite loss (Bruce & Schultz, 2001). Together these concepts reveal that losing a loved one’s self is not defined by physiological death. Rather, losing a loved one’s self takes the perspective of the perceiver and, although the loved one is alive and present, describes the marked change and loss of the spirit, or essence, of the person. In addition, literature which considers loss and grief in relation to losing the perception of a loved one’s self was considered, in particular disenfranchised grief (Doka, 2002a; Doka & Aber, 1989) and anticipatory mourning (Rando, 2000c). This literature has raised the possibility that marked changes to a loved one’s self may lead family members to endure deep personal losses and complicated grief.

**Summary and Conclusion**

Based on the research question for the study, literature relevant to understanding human experiences of delirium have been reviewed and discussed in this chapter. A range of sources and perspectives have been drawn upon to explore delirium in older people, moving beyond the disease perspective presented in Chapter 1: Study Introduction. Consistent with the research question a particular emphasis has been placed on reviewing current understandings of family member experiences during their older loved one’s delirium. A range of family member reactions to their experience are discussed highlighting the distress they feel and how their experiences are confronting and overwhelming. Heightened family member awareness of the changes that occur in the person with delirium and how the rapidity of these changes is felt by family members of older people is highlighted when considered with experiences of family members with loved ones receiving palliative/advanced cancer care or during dementia. The review also highlights that family members may fear their loved one will be viewed as “mad” or that death may be close. Staying connected to the familiar person during episodes of delirium appears to be important. Family members try to reach and find the person they know and trust, to re-establish the person’s trust in them.
and to communicate prior to death. Understanding what is happening and how to be with the person during delirium also appears to be important.

This chapter also considered delirium as experienced by older people and nurses. The perspective of older people revealed their experiences to be frightening and characterised by changing realities which can be dismissed or negated by family or health care staff. Communication is problematic for older people during these times. Trust is discussed as a central concern for older people and the possibility of delirium being linked to insanity was raised. The reactions of older people after an episode of delirium were described, including concerns about accounting for their odd or uncharacteristic behaviours. When considering nurses’ experiences it is noted that nurses frequently describe stress, distress and feeling pressured when they care for patients in delirium, relating these feelings to the fluctuating nature of delirium, perceived increases in workload and care priority conflicts. Highlighted is a focus on the older person rather than concurrently considering the experiences and needs of family members.

By locating the study in the context of what is known about human experiences of delirium this review supports the significance of the study and validates why family member experiences during a loved one’s delirium warranted further investigation within Australia. The review of the literature revealed that older person delirium has considerable impact on family members, supporting the argument that insights into family member experiences during their loved one's delirium are important for health care staff and can assist them to understanding family member needs. Only one qualitative Swedish study which explored the lived experience of being a family member of an older person who has delirium and one small day centre study were identified to inform health care staff understandings. Although a beginning understanding of family member experiences was evident from these studies, alone they did not adequately describe the meaning of this experience from the perspective of family members. Family member experiences and perceptions needed to be brought further into view and taken into account in health care as an important dimension to caring and providing compassionate and contextualised older person care.

Guided by the analysis of participant experiences in this study, the review also presented and discussed research into family member experiences of losing a loved one’s self during ADRD and theoretical literature which conceptualises the loss or absence of a another person’s familiar self. This literature suggests that the experience
of losing a loved one’s self is linked to grief and mourning and that there are shared qualities to family member experiences of love one’s with delirium and dementia.

The next chapter presents the methodology used to explore the experience of family members who are with their loved one during delirium. In this discussion Sartre’s (1943/2003) notion of *absence* is explored to inform analysis of participant experiences.
CHAPTER 3: GUIDING APPROACH
Chapter Introduction

The previous chapters have located the study within the context of published literature about experiences of delirium. An interest in, and need to better understand, the perspectives of family members who experience their older loved one during delirium was recognised. In this chapter existential phenomenology is presented as the approach used to guide the study undertaken to address this need. The reasons for adopting phenomenology and the tenets fundamental to the application of existential phenomenology to research are presented and discussed. Particular attention is given to the philosophical views of Sartre (1943/2003) and Merleau-Ponty (1945/2002), as their writings informed the approach used. The discussion that follows lays open the theoretical paradigm underpinning the study, the stance I took as a researcher and the basis upon which meanings have been interpreted from the experiences shared by family members in this study.

Selecting the Guiding Approach

In order to better understand how different research methodologies might enhance current ways of understanding delirium and the meaning of family member experiences, time was taken to fully appreciate the characteristics and assumptions of different research paradigms. While coming to understand and appreciate these different perspectives, I held the question I wanted to answer and the aim of the study in my mind (see Chapter 1: Study Introduction). I was aware that my aim and the nature of my research question pointed to an approach that supported a humanistic orientation and which focused on subjective experiences; I wanted to more deeply understand the perspective of family members when they experienced being with their older loved one during delirium and to uncover deeper meanings. The intent was to be sensitive to the lives of family members; to privilege their perspectives and to go deeper than simply knowing the factual elements of their experience. This intent was important as consideration of the literature (see Chapter 2: Literature Review) revealed that though delirium was well understood from a disease, biomedical or objective perspective, there had been little exploration of family member experiences to offer what van Manen (2007) describes as pathic forms of understanding: understandings that resonate with the body and are situational, relational, and temporal. Taking on Morse and Field’s (1995, 1996) position that research approaches from the qualitative paradigm are particularly suited when current knowledge is skewed in orientation, I confirmed that the research question was not suited to exploration using quantitative
research approaches. Rather than causal explanations or prediction based on isolated variables in large numbers of people, the research question called for interpretation and the understanding of meaning from experiences for a small number of specific people in a particular situation. It was also important that family members and their experiences were not decontextualized or reduced to parts which are investigated separately, discretely or solely through categorisation by an outsider. Hence my attention focused on different ways to explore situated human experiences using qualitative research methodologies.

The Qualitative Research Paradigm and Phenomenology

In general, qualitative research approaches consider and richly describe the social world and search for the meaning of human experiences or reality (Morse & Field, 1995). They generally answer questions which ask what a particular experience is like and aim to make this reality understandable to other people (Morse & Field, 1995). Rather than measurement and explanations, methodologies in this paradigm use an emic exploration of everyday reality within a naturalistic setting, accept multiple realities, create detailed descriptions of whole experiences and inductively develop understanding over time (Morse & Field, 1996; Moustakas, 1994; Stewart & Mickunas, 1974). With an emphasis on interpretation, the ontological assumptions underpinning qualitative research were in keeping with my interest in the experiences of family members and the research question. These assumptions were that people actively and meaningfully engage in the world and construct their own realities, and that human reality is emergent, situational and the result of continuous definition and redefinition (Daly, 2007; Munhall, 2007).

The qualitative research paradigm includes a range of methodologies with diverse origins, including linguistic analysis, social theory and philosophy (Creswell, 2007). It includes methodologies suited to inquiring into human experience, such as narrative inquiry, phenomenology and case study (Creswell, 2007). Although different qualitative methodologies could give an account of family member experiences during delirium, each addresses different questions about the nature of human experience. A grounded theory approach considers social processes and ethnography focuses on culture, tradition and power imbalance (Cohen et al., 2000; Creswell, 2007). What I sought was an approach that provided a way into the world of family members, which explored taken-for-granted experiences and helped to bring their meaning into view. To enable me to explore the phenomenon of delirium in older people from the perspective of
family members themselves, existential phenomenology was used as the guiding approach for the study.

Located within the qualitative research paradigm the intent of phenomenological research, including existential phenomenology, is different to research using empirical approaches (Creswell, 2003). The aim is not to develop theoretical truths or create generalisable facts for evaluation against normative constructs (van Manen, 1990). Rather, as Merleau-Ponty (1945/2002) argues, phenomenology is “a matter of describing, not of explaining or analysing” (p. ix). Instead of viewing experiential accounts through theoretical frameworks, phenomenology asks the researcher to move to a phenomenological way of thinking, to reflect on these accounts and, through a back and forth process of reflection and hermeneutical interpretation, develop rich written texts which communicate the meaning of experiencing phenomena (Finlay, 2009; van Manen, 1990). The expressed meanings are intended to communicate what it is that “makes a some-‘thing’ what it is [sic]-and without which it could not be what it is” (Husserl & Merleau Ponty cited in van Manen, 1990, p. 10). These meanings also have an authenticity which “reverberates with our ordinary experience of life as well as with our sense of life’s meaning” (van Manen, 2007, p. 26).

By seeking a description which more fully revealed the meaning of family member experiences during their loved one’s delirium I also aimed to generate what van Manen (1990) calls “action sensitive knowledge” (p. 21). As our own understandings of the world are primarily based on our own perspective (Merleau-Ponty, 1945/2002, p. ix), understandings gained through phenomenology are of value in health care as they enhance our ability to be attentive to other people's experiences of illness. Merleau-Ponty (1945/2002, p. vii/ix) argues that the phenomenological perspective promotes thinking which considers people to be their own absolute source of meaning. In his view phenomenology puts human meaning back into the way the world is understood by focusing on human knowledge of the world before scientific explanation, distilling the invariable feature of a particular object of human experience. By understanding and being moved by the individual’s situation (Dreyfus, 1994; van Manen, 1990), a phenomenological exploration of family member experiences aids the development of existential knowledge that can enhance health care staff awareness of the impact of an older person’s illness on family members. These pathic understandings have the potential to assist health care staff to respond to family members with sensitivity and compassion.
The strength of existential phenomenology as a guiding approach for the study over other qualitative approaches lay in the way it turned and focused my attention on the experience and world of family members themselves; to uncovering reality as it was uniquely and subjectively perceived by them. This approach offered a way to access and engage in respectful conversations with family members about their experiences during their loved one’s delirium and to collect nuanced descriptions; a way to delve into the lived experiences of family members themselves and to explore their thoughts and feelings. Existential phenomenology also provided an opportunity to understand the experiences of family members in a way that moved beyond the facts of the situation and prior conceptualisations; to “speak” to the humanness of living in the world as an older person’s family member. Though other qualitative methodologies focus on human experiences and support the use of conversations with participants, searching for and explicating meaning through the philosophy of existential phenomenology, and the phenomenological attitude, reflection and description makes this approach distinct from other qualitative approaches. In addition, whilst a descriptive phenomenological approach had been adopted to explore family experiences of delirium in the one prior study by Stenwall, Sandberg et al. (2008) (see Chapter 2: Literature Review), a study based in the interpretive phenomenological tradition and on existential phenomenology complemented this earlier work and moved current knowledge and understanding of family member experiences forward by offering another interpretation. As van Manen (1990) argues, no single phenomenological exploration and description of human experience will be exhaustive or definitive; there remains “the possibility of yet another complementary, or even potentially richer or deeper description” (p. 31). Interpretive approaches, as described later in this chapter, offer the opportunity to explore contextual features which have direct relevance to the meaning of family member experiences.

Phenomenology and Existential Phenomenology

An exact definition of phenomenology is hard to find, perhaps reflecting the breadth of positions within phenomenology as a philosophical movement. Observing this problem Merleau-Ponty (1945/2002, p. vii) wrote that phenomenology is at the same time a philosophy of essences and a philosophy that puts essences back into existence; both a philosophy that starts with setting aside conceptualisations of the world and a philosophy in which the world is already there; both a rigorous science and a description of immediate lived life. Ultimately however, for Merleau-Ponty (1945/2002, p. viii) phenomenology is all of this but most importantly it is a manner or style of
thinking that puts to the side conceptualisation, categorisation or theory and facilitates
the search for meaning in human subjective experience. In doing so phenomenology
describes the subjective world of people as lived and increases our understanding of
what it is like to exist as people in a shared world (Benner, 1994b).

Grounded in the original works of early philosophers such as Brentano (1838-1917)
and Husserl (Benner, 1994a; Stewart & Mickunas, 1974), the historical basis of
phenomenology as a school of philosophy is extensive. Over time philosophical
positions within phenomenology have evolved, reflecting different views about the
nature of reality, the relationship of the perceiver to reality, and different knowledge
interests (Annells, 1999). Though there are different philosophical positions,
phenomenology has two broad traditions which bring together loosely related and
overlapping philosophical views; namely the descriptive (eidetic) and interpretive
(hermeneutic) traditions (Cohen & Omery, 1994; Dowling, 2007; Lopez & Willis, 2004;
Ray, 1994). Husserl’s transcendental phenomenology exemplifies the descriptive
tradition and has an epistemological focus (Mackey, 2005; Ray, 1994). His philosophy
aimed to study human consciousness to reveal knowledge which transcended human
experience (Mackey, 2005; Stewart & Mickunas, 1974). Husserl reacted against and
opposed Descarte’s distinction between mind (thinking substance) and body (extended
substance), and the use of doubt to deny the existence of things in the world (Stewart &
Mickunas, 1974). He proposed an understanding of conscious awareness of the
world through pure consciousness, a consciousness freed from all theoretical
presuppositions and interpretations (Stewart & Mickunas, 1974). For Husserl, shedding
prior knowledge of the world purified consciousness, leaving only phenomena to reveal
the basic structure of consciousness itself (Stewart & Mickunas, 1974). Of significance
is Husserl’s view that human life is characterised by radical autonomy enabling us to
exert influence on the world (Lopez & Willis, 2004; Stewart & Mickunas, 1974).
However, Husserl viewed culture, society, and politics as having little influence on
human experience (Lopez & Willis, 2004).

Several philosophers, whose writings align with the interpretive tradition, have focused
on ontological concerns and have modified or extended Husserl’s descriptive
phenomenology. They include Heidegger (1889-1967) who advanced existentialism
and hermeneutics (Luijpen & Koren, 1969/2010), Sartre (1905-1980) and Merleau-
Ponty (1908-1961) who advanced existential phenomenology (Luijpen & Koren,
1969/2010), and Gadamer who advanced Gadamerian hermeneutics (Dowling, 2007).
Rather than focusing on describing what people consciously know as universal
essences, as with descriptive phenomenology, philosophers in the interpretive tradition
appreciate difference in meaning and focused on understanding the meaning of situated human experience (Lopez & Willis, 2004; Luijpen & Koren, 1969/2010; Wojnar & Swanson, 2007).

Existential phenomenology has evolved from, and brought together, the philosophy of phenomenology and that of existentialism (Luijpen & Koren, 1969/2010; Stewart & Mickunas, 1974). Its development has been attributed to Heidegger's “Being and Time”, a philosophical thesis which merged Kierkegaard's (1813-1855) existential philosophies and the phenomenological philosophy of Husserl, particularly his later notion of the life-world (lebenswelt) (Luijpen & Koren, 1969/2010). Other existential philosophers include Levinas (1906–1995), and Marcel (1889–1973).

Existential phenomenology seeks to understand the meaning of human existence by considering people in their concrete, lived situations, including their culture, history and relations with others (Stewart & Mickunas, 1974). Importantly it insists that human reality is situated in the world and, unlike Husserl's descriptive phenomenology, considers human beings to already be in, and unable to separate themselves from, the world (Stewart & Mickunas, 1974). By existence existential phenomenology refers to how conscious-being-in-the-world is the essence of man (Luijpen & Koren, 1969/2010, p. 38) and the way of being which distinguishes human existence from everything else in the world. In existential phenomenology existence is subjective and “existence comes before essence” (Sartre, 1946/2002, p. 27). Sartre (1943/2003) argues an individual first of all is born (or exists) and then chooses what he/she is by virtue of his/her consciousness; man "encounters himself, surges up in the world – and defines himself afterwards" (Sartre, 1946/2002, p. 28). Unlike Husserl’s phenomenology, freedom in the existential perspective is situational, constrained by the conditions of our daily lives and the choices we make, and reflects our capacity to experience hope within difficult experiences (Farran, 1997; Luijpen & Koren, 1969/2010, p. 109). In arguing an orientation which is toward the future, Sartre (1943/2003), like other phenomenologists, introduces a temporal dimension to existence and essence. The past is the facticity of my life as already lived. The future opens up possibilities for my freedom and for what I choose to make of myself.

In philosophising about the meaning of personal existence, existential phenomenology has been concerned with describing the problems of human existence or life situations, and asks questions like “What is it to exist?”, “Are we free?” and “How should we face death?” (Luijpen & Koren, 1969/2010; Priest, 2001; Wojnar & Swanson, 2007). In understanding these questions the existentialist view acknowledges that we will
experience an existential vacuum as part of human existence, so leading to assumptions about existence. These assumptions include being born and dying alone and the inevitability of experiencing isolation and despair during life (Farran, 1997). Further exploration has led to the description of existential truths, or fundamental, irrevocable and inescapable features of human existence, including freedom (Heidegger, 1927/1962; Merleau-Ponty, 1945/2002; Sartre, 1943/2003), anguish (Sartre, 1943/2003), existence of others in a social world (Heidegger, 1927/1962; Merleau-Ponty, 1945/2002; Sartre, 1943/2003), abandonment (Heidegger, 1927/1962), mortality (Sartre, 1943/2003) and responsibility (Sartre, 1943/2003).

As noted previously, existential phenomenology was used to guide this study to completion. The approach taken was informed by the philosophies of Sartre (1943/2003) and Merleau-Ponty (1945/2002), with particular emphasis on Sartre’s “Being And Nothingness” (1943/2003) and Merleau-Ponty’s “Phenomenology Of Perception” (1945/2002). Also consulted were Sartre’s “Existentialism And Humanism” (1946/2002) and “The Transcendence Of The Ego” (1957/1991), and Merleau-Ponty’s “The World Of Perception” (1948/2004) and “The Visible And The Invisible” (1968). As all these texts were steeped in the complexities of philosophical argument and were translations of original works written in French, I also derived my understanding of existential phenomenology by co-reading commentaries or guides. For example, Luijpen and Koren’s (1969/2010) text on existential phenomenology, Stewart’s (1998) text on the philosophies of Sartre and Merleau-Ponty, and Gregory McCulloch’s (1997) discussion of early Sartrean themes. When considering the design and methods to be employed during the study, the work of van Manen (1990) and Munhall (1994, 2007) were adapted and applied to support the translation of existential phenomenology as philosophy into research design and methods, a translation described in Chapter 4: Study Design and Methods.

In the following section the main philosophical arguments of Sartre (1943/2003) and Merleau-Ponty (1945/2002) are briefly described.

**The Philosophies of Sartre and Merleau-Ponty**

The philosophical career of Sartre (1905-1980) is characterised by a desire to understand human existence (McCulloch, 1997). His interest was in describing human beings and their world as they appear to consciousness or as they can be experienced, so reconciling the object and the subject (Cohen, 1987; McCulloch, 1997). In presenting an individualist ontology, Sartre hoped to transform lives by denouncing
conformism and providing a philosophy of freedom; a philosophy which called on each person to live an authentic life, one that was in line with the values they freely and autonomously endorsed rather than had imposed on them by society (Levy, 2002). His main idea was that people are condemned to be free (Spiegelberg, 1960), a characteristic of human existence which contrasts with the existence of material things (Levy, 2002; Stewart & Mickunas, 1974). In Sartre’s conception freedom takes a positive tone, referring to people’s freedom to make choices and act in certain ways, choices for which each person is responsible (Stewart & Mickunas, 1974). Furthermore Sartre’s phenomenology maintains that people are fundamentally motivated by life’s project or what they make of themselves, referring to the existential argument that existence precedes essence (Luijpen & Koren, 1969/2010). In Sartre’s view the origin of this project is spontaneous original choice which stems from individual freedom and the way that choice evolves; either living authentically or avoiding taking self-responsibility (bad-faith). His ontology describes the fundamental nature of reality as being made up of two different kinds of things; in-itself (or material entities) and for-itself (the conscious free self) (Levy, 2002, p. 29). He extends his ontology to include being-for-others, a non-distinct entity, to reflect people’s existence for other people and the curtailment of individual freedom by the social world (Levy, 2002; McCulloch, 1997, p. 37). Research guided by Sartre’s philosophy examines human existence prior to idealised essences (Cohen, 1987).

Like Sartre, Merleau-Ponty was a French philosopher and linked his existentialism to Husserl’s work (Cohen, 1987). However, Merleau-Ponty claims that his philosophy evokes unthought-of elements to Husserl’s work and, through the advancement of anti-Cartesian thought, argues that perception is the primary mode of consciousness (Romdenh-Romluc, 2011). For Merleau-Ponty (1945/2002) objective thought dominates existing ways of understanding the intersubjective world of things and a new way of perceiving the world is needed to better understand the human world. In his view we live a paradox; our dominant understanding of things is imperfect and yet it prevents true understanding of the world (Romdenh-Romluc, 2011). Like Sartre (1943/2003), Merleau-Ponty (1945/2002) challenges the traditional dualist distinctions between mind and body, and people and things. The aim of his philosophy is to unite these traditionally separated realms of existence in one conceptual whole, and therefore to provide a new way of conceiving and thinking about the nature of consciousness, the world and their relation (Merleau-Ponty, 1945/2002; Romdenh-Romluc, 2011). His philosophy argues against objective thought and presents embodied perception as the primary means of understanding human existence in a
shared world (Romdenh-Romluc, 2011). In contrast to Sartre’s (1943/2003) phenomenological focus on the notion of human freedom, Merleau-Ponty argues “we are condemned to meaning” (1945/2002, p. xix).

In the study reported in this thesis, the philosophical arguments of Sartre (1943/2003) and Merleau-Ponty (1945/2002) were central to the way the research question was explored and the experiential descriptions of family members were collected, analysed and interpreted. Though the philosophies of Sartre (1943/2003) and Merleau-Ponty (1945/2002) do not form a single cohesive thesis, their existential philosophies share broad beliefs or tenets about lived experience and what it is to be human (Luijpen & Koren, 1969/2010; Stewart & Mickunas, 1974). Many of these tenets have origins in the earlier philosophies of Brentano (1838-1917), Husserl (1859-1938), and Heidegger (1889-1967) (Moran, 2000), and include a return to things themselves and the concepts of consciousness, intentionality, perception, embodiment, intersubjectivity, lived world, taken-for-granted, natural attitude, bracketing and meaning or essence. In addition, several notions particular to the writings of Sartre (1943/2003) and Merleau-Ponty (1945/2002) were central to the conduct of this study. Merleau-Ponty’s (1945/2002) arguments about the perceived world, and Sartre (1943/2003) and Merleau-Ponty’s (1945/2002) arguments about the lived body and the body of others aligned with the research question, resonated with the data and spoke to the meaning of family member experiences during data analysis and interpretation, so helping me to understand at a deeper level. In particular, there was a connection between the intimate nature of family member relationships with their older loved one and Merleau-Ponty’s (1945/2002) writings on intersubjectivity, a concept that was richer and more aligned to family member relationships with their older loved ones than Sartre’s (1943/2003) writings on this subject. Both were helpful in coming to understand the changes which family members described during their loved one’s delirium, in particular Sartre’s (1943/2003) notion of the look, Merleau-Ponty’s (1945/2002) inhuman gaze, and existential consideration of otherness. As themes emerged during the analysis of study data, Sartre’s (1943/2003) exploration of expect, lack and absence resonated with the experiences family members described. The following discussion elucidates these tenets and describes how they are explicated by Sartre (1943/2003) and Merleau-Ponty (1945/2002). In doing so the philosophical basis for the study is disclosed, including how human existence, the world, people and relations with other people have been conceptualised. It also reveals how existential phenomenology has been applied to shape the study’s design and methods, and guided the way family member experiences were explored and interpreted.
Returning to Human Experience of Things Themselves

Drawn from Husserl’s early work, phenomenology continues to invite us to return to \textit{things} themselves (Stewart & Mickunas, 1974); to direct full attention to human experience of \textit{things} in the world so that we may better understand what it is like to live a human existence (Merleau-Ponty, 1945/2002; Sartre, 1943/2003). For Husserl, anything in the world that announces itself and we are aware of are \textit{phenomena} or \textit{things} (\textit{Sachen}) (Stewart & Mickunas, 1974). No matter if the appearance of these \textit{things} to our \textit{consciousness} is an object, event, situation or an imagination (Cohen, 1987), they are the basis for all our knowledge (Stewart & Mickunas, 1974). In taking this stance, attention is on what is given to us in \textit{conscious awareness} rather than our prior knowledge of \textit{things} which has come from scientific conceptualisation, categorisation and casual explanation (Merleau-Ponty, 1945/2002; Sartre, 1943/2003; van Manen, 1990). In Merleau-Ponty’s (1945/2002) view, a return to \textit{things} is a “return to that world which precedes knowledge, of which knowledge always speaks” (p. x), emphasising the pre-reflective nature of everyday experience and lived human meaning.

When conducting this study, a return to \textit{things} themselves meant that I deeply reflected upon and explored the experiences of family members using a phenomenological stance; a stance that broke with day to day orientations and attended to the humanness or live qualities of the experience for family members. As described in Chapter 1: Study Introduction, delirium had been on my mind for some time and I wanted to take time to focus on what family members had to say about their experiences and to understand what it was like from their perspective rather than know delirium as a condition or illness in older people. Once committed to this exploration a phenomenological understanding of the \textit{intentionality} of \textit{consciousness} and its relationship to experience was used.

\textbf{Consciousness and Intentionality}

Existential phenomenology considers \textit{consciousness} to be human conscious awareness of the world through the body (Merleau-Ponty, 1945/2002). \textit{Consciousness} is therefore not thought of as a separate entity, but as having a unity with the body, so establishing a means to act in and experience the world (Grbich, 2007; Munhall, 2007). \textit{Consciousness} is also considered to intend to, or about something (Husserl, 1999; Merleau-Ponty, 1945/2002; Sartre, 1943/2003), revealing \textit{consciousness} to have a certain structure that characterises all conscious acts. This structure is known as the
intentionality of consciousness and is one of the tenets for which Husserl is well known (Stewart & Mickunas, 1974). It is also a tenet continued in the existential philosophies of Sartre (1943/2003, 1957/1991) and Merleau-Ponty (1945/2002, 1948/2004).

*Intentionality* refers to the nature of consciousness, to its directedness or how consciousness points to *things* in the world, and to the human experience of being conscious of *things* (Merleau-Ponty, 1945/2002; Sartre, 1943/2003). Although the common meaning of “intent” or “intend” implies deliberate effort, for phenomenology intentionality is unavoidable and is implicit in everyday human awareness of the world (Merleau-Ponty, 1945/2002; Sartre, 1943/2003). Through its implicitness the intentionality of consciousness is a taken-for-granted aspect of human existence, one that needed to be explored when seeking the meaning of family member experiences in the study.

The *things* consciousness intends towards are what we see, hold, think about, and image in our daily life and our conscious awareness of these *things* reveals what is meaningful at a particular time, in a particular place and in relation to other people. However, Merleau-Ponty (1945/2002) also argues that consciousness is at times directed towards *things* even though there is no obvious intentional object. Such implicit intentional consciousness is shown in how we act, with each action revealing intentional threads (Merleau-Ponty, 1945/2002, p. xv/150) which link consciousness, the body and *things* in the world.

Phenomenology also argues that the intentional nature of consciousness expresses the unity of mind and body by revealing that the relationship between the body and the world is consciousness (Merleau-Ponty, 1945/2002; Sartre, 1946/2002; Stewart & Mickunas, 1974). As consciousness is of something in the world, the inner and outer human worlds are always bound together as one (Stewart & Mickunas, 1974). As expressed by Merleau-Ponty (1945/2002) consciousness is opened toward the world and is something in the world. However, unlike the mental substance proposed by René Descartes, a substance which exists in its own right and separately to the body (Stewart & Mickunas, 1974), Sartre (1943/2003) views intending consciousness as embodied but nothing in itself. For Sartre (1943/2003) consciousness is directed outside itself with the *thing* that it intends and does not draw the *thing* it intends into itself from the world; using the example of a table Sartre (1943/2003) makes the point that we do not experience what we are looking at as being in our brain. We perceive it out in the world and in space, beside that window for example. For Sartre (1943/2003) consciousness is always empty and is characterised by, and is the source of,
nothingness. Things that appear to us are hence for consciousness rather than in consciousness (Sartre, 1957/1991).

The emphasis phenomenology places on returning to things focused consideration during the study on human involvement in the world and on explicating the way in which family member experiences are directed conscious awareness of things. In this study the thing or phenomenon of interest was family member experiences when with their loved one during delirium. This focus meant that family members in the study had experienced a loved one during delirium and, when asked, were able to recall and describe their experiences during interview conversations. In the phenomenological sense, family member descriptions of their experience were an expression of their conscious awareness of the world during delirium, always being about or of someone or something. Of interest were objects of family member consciousness and their appearance or givenness to family members within their situation. Each family member’s intentional awareness revealed what was meaningful to them at that time, in that place and in relation to other people. This provided material from which phenomenological themes were developed and helped me to grasp of the meaning of their experiences. As phenomenology argues experience is made available through conscious awareness of the world, perception and its role in attending to things in the world was an important dimension to understanding family member experiences.

Perception

The stance taken by phenomenology is that what is given to me in my perception of things is their appearance for me, revealing phenomena as they appear in my world (Moustakas, 1994). The role of perception in the appearance of things is central to Merleau-Ponty’s (1945/2002) philosophy, where he considers perception to be the original mode of experience and an ongoing process which explores and discovers the world (Romdenh-Romluc, 2011). Perception, in Merleau-Ponty’s (1945/2002) view, “throws me open to a world” (p. 439), and is the presupposed background through which I am afforded access to things. Merleau-Ponty (1945/2002) argues that the things we perceive are constituted in our perception of them, such that through perception the world becomes human experience or individual subjective reality; “for just as it is the means whereby objects are distinguished from each other, it is also the means whereby they are disclosed for me” (Merleau-Ponty, 1945/2002, p. 79). Perception then is “how we delve into the thickness of the world” (Merleau-Ponty, 1945/2002, p. 237), thus giving access to what is lived through and grounding knowledge in the lived world (Merleau-Ponty, 1945/2002, p. xviii).
When *consciously aware* of *things* in the world they appear situated and, according to Merleau-Ponty (1945/2002, p. 78), they are experienced as a figure against a background. What stands out as figural cannot however, be fully understood without considering the *horizon* or background that serves to delineate its experiential form, and how the figure/background relationship moves during our experience of *things* (Merleau-Ponty, 1945/2002). The horizon is what “guarantees the identity of the object throughout exploration [...] for just as it is the means whereby objects are distinguished from each other, it is also the means whereby they are disclosed” (Merleau-Ponty, 1945/2002, pp. 78-79).

In Merleau-Ponty’s (1945/2002, p. xviii) view, perception involves a perceiving subject in a situation, rather than a spectator who takes an objective stance. What appears in perception is then always from the *perspective* or vantage point of the subject perceiver, varying in tune with factors such as the angle, time, context, background and orientation of the perceiver (e.g. judging, wishing or expecting) (Merleau-Ponty, 1945/2002; Moustakas, 1994, p. 29). Our view and experience of *things* is therefore always egocentric or mine; as expressed by Merleau-Ponty “all my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view” (1945/2002, p. ix). Importantly, for Merleau-Ponty (1945/2002) perspective is no obstacle to seeing *things* in the world and is not a bias. It is how the world is lived.

Sartre’s (1943/2003) arguments on perspective are similar to Merleau-Ponty’s (1945/2002). In Sartre’s (1943/2003) view there is no such thing as a description of something without a perspective. In his view the world is revealed for me as an *appearance* from my unique viewpoint, the very act of perceiving requiring the engagement of my unique perspective. The appearance of *things* through my perspective gives *things* in the world their structure or their *thisness* for me, for example their spatiality, presence and motion. Sartre (1943/2003) argues that it is through my perception and perspective that the world is significant and meaningful to me.

Perception has an emotional dimension for Merleau-Ponty (1945/2002) and Sartre (1943/2003). Merleau-Ponty argues that feelings infuse the content of our perceptions and are therefore aspects of how we perceive the world (Romdenh-Romluc, 2011), and Sartre argues that emotions colour *things*, making us perceive *things* in the world in a particular way (McCulloch, 1997). Exploring the notion of *looking familiar*, Merleau-Ponty argues that familiarity is not captured only through the perception of a set of properties (Romdenh-Romluc, 2011). Rather he argues that for something in our world
to look familiar it needs to feel familiar, a perception in which the feelings of familiarity infuse and alter the thing looked at. The feeling of familiarity is therefore inseparable from the thing being perceived (Romdenh-Romluc, 2011).

These ideas point to the individuality of perception during delirium, the importance of contextual dimensions of perception and also to variation in the way different people perceive the world during this time, all aspects to family member experiences that were important when coming to understand their meaning. As revealed in the following chapters, for the family members in the study the familiarity of their loved suddenly changes during delirium, a change which is seen and felt and dominates their experience.

When considering perception Merleau-Ponty (1945/2002, p. 239/389) also describes the experience of hallucinations and, in doing so, supports his argument that the perceived world is not only my world but also a world shared with other people (Marshall, 2008). Importantly for understanding the experiences of family members in the study, Merleau-Ponty argues that by calling other people’s perceptions hallucinations, I reveal that what the other person perceives is not the same as my experience (Marshall, 2008). The hallucinations are given-to-me as something I cannot see; as not real and disconnected from the natural world. At the same time I am aware that they are given to the other person as open to them (Marshall, 2008). As Merleau-Ponty says:

I am therefore aware of apprehending, through hearing and particularly through sight, a system of phenomena which makes up not only a private spectacle, but which is the only possible one for me and even for others (...) the victim of hallucination enjoys no such belief (...) Hallucinations are played out on a stage different from that of the perceived world, and are in a way superimposed (...) the hallucinatory thing is not, like a real thing, a form of being with depth. (1948/2004, pp. 394-395)

Embracing existential phenomenology as an approach to explore family member experiences required a belief in the uniqueness of each person’s perception and perspective on the phenomena being considered. This meant understanding that different people may describe the experience of interest to the study in different ways, even if in the same family, were the same gender or experienced at the same time and
in the same context. Individual family member perceptions were what mattered, not what I or others may have thought they should have experienced. For example, the following chapters show that some family members perceived their loved one to be crazy, a perception which may be considered untrue if considered from a medical perspective. Similarly through experiencing their loved one’s illusions and hallucinations family members describe living with two realities, even though objectively they considered there could be but one. Also important was considering what was figural and background for family members throughout their experiences. Family member descriptions disclosed what was the focus of their attention at different times, disclosed aspects of the background and revealed changes to their experience as time passed. Thinking about multiple and different experiences and asking what was the meaning of these experiences became a way of working.

Although perception is a central tenet in phenomenology, Merleau-Ponty (1945/2002) argues that perceptual experience cannot be detached from the intentionality of consciousness and consciousness as an embodied experience of the world. In his view we become aware of an aspect of the world and are conscious of something through the opportunities offered to us through embodied perception. The body therefore has an integral place in Merleau-Ponty’s (1945/2002) philosophy of perception, as it does in Sartre’s (1943/2003) philosophy. In considering the experiences of family members during their older loved one’s delirium, it was therefore important to consider bodily dimensions of perception and experience, particularly bodily perception of other people in the world.

**Embodiment and Relationality**

The importance of the body, or the corporeality of consciousness (1945/2002), in understanding human experience is a recurrent theme in existential phenomenology, as it was in Husserl’s descriptive phenomenology (Stewart & Mickunas, 1974, p. 65). However, it is Merleau-Ponty who gives extensive consideration to the body and to breaking down Cartesian mind-body dualism (Fjelland & Gjengedal, 1994). Both Merleau-Ponty (1945/2002) and Sartre (1943/2003) argue that as embodied beings we are situated, encounter other people and experience the world. They share a view that there is a distinction between the body as object, the body as subject (or as lived), and the body as perceived by others who share the world. How Merleau-Ponty (1945/2002) and Sartre (1943/2003) express embodiment and how we encounter the body of other people does however differ. Although Sartre (1943/2003) and Merleau-Ponty (1945/2002) present different arguments about embodiment and our relations with
other people, the way their arguments challenged taken-for-granted ways of understanding perception was important in exploring the meaning of family member experiences. In this study, taking an existential view of embodiment, perceiving the body of others and being perceived by others provided a lens for considering and questioning the experiences of family members, experiences which were situated in the context of relating to loved ones and to health care staff. As illustrated in Chapter 6: Findings, insights from Merleau-Ponty’s (1945/2002) and Sartre’s (1943/2003) perspectives helped to unveil the meaning of family member experiences during their loved one’s delirium, particularly understandings of a loved one’s existential absence (Sartre, 1943/2003) and encountering a stranger.

**Body as Subject**

Central to Merleau-Ponty’s (1945/2002) philosophy is the view that the body is a subjective form of consciousness. In this view the body cannot be thought of only as a thing or an object which is like other physical objects in the world. Taking perception as the central tenet to his philosophy, Merleau-Ponty (1945/2002) argues that the body is our continuous condition of experience and, as such, perception of the world; he says “the body is our general medium for having a world” (p. 146). By arguing that the body is the corporeality of consciousness and that the intentionality of the body is a natural and integral part of consciousness, Merleau-Ponty’s (1945/2002) philosophy contrasts with the dualist mind body view of René Descartes.

Merleau-Ponty (1945/2002), like Sartre (1943/2003), begins his discussion of embodiment with the unity of mind and body and argues that there are different manifestations of the body which need to be distinguished to understand the meaning of human relations (1943/2003, p. 327/330). Central to Merleau-Ponty’s (1945/2002) philosophy is the subjective body or the phenomenal body (Merleau-Ponty, 1945/2002, p. 121). Unlike the body of another person, the phenomenal body is experienced from the inside and not as though a material object (Matthews, 2010). In this view what I experience is “my” subjective body and is the way that “I” make contact with things so that there is a world for “me”; in touching another person “I” touch, in seeing how another person acts “I” see their actions, in hearing what another person says “I” hear.

Merleau-Ponty’s (1945/2002) philosophy presents the phenomenal body, or bodily subjectivity, as a unified and internally related system of sensory input, one which is beyond the sensory experience of seeing, feeling, tasting, or hearing. In his view bodily subjectivity is integrated and occupies me in perceiving, bringing into existence things in the world (Merleau-Ponty, 1945/2002, p. 276/278). Through embodied contact with
objects in the world, *things* around me are experienced and have practical, emotional and imaginative meaning; the whole body is pathic and the body knows. As Merleau-Ponty (1945/2002) wrote:

> My body is the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of my “comprehension”. It is my body which gives significance not only to the natural object but also to cultural objects like words. (Merleau-Ponty, 1945/2002, p. 237)

Merleau-Ponty (1945/2002) contrasts this phenomenal body with the other person’s body as experienced by me and, through example, the objectified and dehumanised body considered in medicine. He also argues that memories of past perception or experiences are embodied and, when recalled, evoke the situation and reopen time lost. Embodiment in his view entails an awareness of past and present, or temporality. Similarly Sartre (1943/2003) argues that recalled *things* from past life are not imagined. They are recalled by me by directing my *consciousness* to the past where the experience is brought out of retirement and is lived as *given-now-as-in-the-past* (Priest, 2001, p. 96).

Sartre (1943/2003, p. 327/330) begins his discussion of embodiment with the unity of mind and body and then argues that there are three bodily manifestations or orders of reality which, though argued as supporting the unity of mind and body, attract criticism in the literature for returning to a dualist philosophy reminiscent of René Descartes (Stewart & Mickunas, 1974; Stewart, 1998). Sartre’s first manifestation of the body is the body as it is for me (*being-for-itself*), a manifestation which is subjective and dominates the perspective offered by other bodily manifestations (Sartre, 1943/2003). Like Merleau-Ponty’s (1945/2002) *phenomenal body*, this view refers to “my” body, “someone’s” body, a body which is experienced in a unique way from the inside and known as mine (Sartre, 1943/2003, p. 328). In this manifestation Sartre (1943/2003) also argues that from within my body is engaged in *consciousness of things* in the world and does not appear to me as other people’s bodies do. My subjective body perspective is dominant and leads me to pass my physical body by, somewhat unnoticed in everyday experience of the world (Sartre, 1943/2003, p. 354).

*Other People and Intersubjectivity*

After considering the body as lived from the inside, Sartre (1943/2003) and Merleau-Ponty’s (1945/2002) philosophies are consistent in that they view living in the world as
coexistence and co-presence with others; a consciousness of other people which involves intentional awareness of them as someone who is a subjective person like me, but one who remains separate to me. As the-other who is in-the-world-with-me (Merleau-Ponty, 1945/2002; Sartre, 1943/2003) I am aware that their body is coexisting with my body and that my relationship with them is one of co-presence (Moustakas, 1994). As Merleau-Ponty (1945/2002) wrote, being in the world “exposes me to the gaze of others as a man among men or at least as a consciousness among consciousnesses” (p. xiv). Consciousness, or experience, therefore includes an intentional awareness of other people, so referring to co-existence and the intersubjective relationship of my existence to other human existences in the world; in the study primarily the intersecting subjective worlds of family members, their older loved ones and health care staff. Intersubjectivity is a key notion supporting the importance existential phenomenology places on the body and embodied existence (Stewart & Mickunas, 1974, p. 65).

When considering existence in a social world, Merleau-Ponty (1945/2002, p. 419; 1948/2004) argues that other people are not considered to be like other objects in our world, simply or only material bodies. This is despite his acknowledgment, like Sartre (1943/2003), that our body and the body of others are also objects; he says “I regard my body, which is my point of view upon the world, as one of the objects of that world” (Merleau-Ponty, 1945/2002, p. 81). Rather, other people are considered to be like me, also embodied, and are perceived as being a person or having “a spirit which haunts a body” (Merleau-Ponty, 1948/2004, p. 62). Though the body of the other person is experienced from the outside, it is the body of another subject and is “hers”, “my friends” (Luijpen & Koren, 1969/2010, p. 35) or, for the family members in this study, “my husband’s” or “my mother’s/ father’s”. Being in the world together is therefore rich with reciprocal intersubjectivity and reveals being-through-others as an essential characteristic of being human (Luijpen & Koren, 1969/2010, p. 146). Co-existing we have all kinds of relations with one another that depend on mutual recognition as subjects who share the same world.

However, Sartre (1943/2003) and Merleau-Ponty (1945/2002) have different orientations to our experience of other people. Sartre’s (1943/2003) focus centres on the experience of being looked at by other people (the look) and conflict or alienation in relationships, whereas Merleau-Ponty (1945/2002) views other people as beside me and in a reciprocal relationship with me (intercorporeality), emphasising an experience of harmony and community (Dastur, 2011). Merleau-Ponty (1945/2002) argues further that consciousness can be simultaneously body-as-subject and body-as-object, or the
chiasm (Merleau-Ponty, 1968, p. 130). The chiasm reflects the coming together of interiority and exteriority that constitutes the body and draws attention to the knot or network of relations lived with others in everyday life; to the influence of another person’s gaze at me and me at them in forming embodied existence (Merleau-Ponty, 1945/2002, p. 456). In Merleau-Ponty's (1945/2002, 1948/2004) social world my understanding of self always involves the seeing of what others see in me. Understanding self is hence a profoundly social learning, arising out of my own corporeality, the corporeality of other people and of their gaze directed back upon me; their look-back-at-me. At the same time understanding others through my own corporeality and my gaze directed at them. Through the interplay of perceiving others and being perceived by others, we live the world together as co-subjectivities supplementing each other (Merleau-Ponty, 1945/2002, 1968); “the seer and the visible reciprocate one another and we no longer know which sees and which is seen” (Merleau-Ponty, 1945/2002, p. 139). Hence Merleau-Ponty (1945/2002, 1948/2004) argues that I come to see the world not only through my own eyes but also as the other sees it, a natural empathy where my body takes up the affective responses of the other person and I assume their perspective along with mine. As Merleau-Ponty (1945/2002) wrote:

It is precisely my body which perceives the body of another, and discovers in that body a miraculous prolongation of my own intentions, a familiar way of dealing with the world. Henceforth, as the parts of my body together comprise a system, so my body and the other persons are one whole, two sides of one and the same phenomenon, and the anonymous existence of which my body is the ever-renewed trace henceforth inhabits both bodies simultaneously. (p. 412)

In Merleau-Ponty’s (1945/2002) view I can come to know another person as far as their embodied consciousness is available to me in their glances, gestures or speech and I am always aware of another person in their situation as though a whole (Merleau-Ponty, 1945/2002, 1948/2004). I hence come to know them from an angle; as given-to-me by my own perspective (Merleau-Ponty, 1945/2002). However, Merleau-Ponty (1945/2002) also argues that through consciousness I cannot know others to the same extent or in the same way I know myself; I only know them through my conscious awareness of them. My thoughts, feelings and actions are distinct from those of other people and I cannot have theirs; I can know of their tiredness or joy but I do not feel theirs as I feel my own. I cannot penetrate their consciousness because it is the
consciousness of another person and our situations and perspectives are never truly the same (Merleau-Ponty, 1945/2002, p. 415). In this study family member descriptions were rich with understandings of their loved one from their perspective as daughters or wives, understandings which were uniquely theirs and had been built over years of co-existence and relating.

Merleau-Ponty (1945/2002) also argues that though I can know other people from my perspective, our co-existence and intersubjective connection are not fixed. In his view co-existence must be experienced reciprocally or our interworld world will be lost and we will both retreat to our separate worlds (Merleau-Ponty, 1945/2002, p. 416). For example, when the other’s gaze becomes an objectifying inhuman gaze (Merleau-Ponty, 1945/2002, p. 420), or when the other person turns away from me, as during the experience of family member’s in the study. As Merleau-Ponty (1945/2002) wrote:

The other’s gaze transforms me into an object, and mine him, only if both of us withdraw into an inhuman gaze, if each of us feels his actions to be not taken up and understood, but observed as it they were insect’s. This is what happens, for instance, when I fall under the gaze of a stranger. But even then, the objectification of each other’s gaze is felt as unbearable only because it takes the place of possible communication. (p. 420)

Thus for Merleau-Ponty (1945/2002) there are ways in which we turn away from being in the world with others and a key aspect of being in the world with other people is our capacity to cope when this happens; to withdraw from a situation and enter a new one as situations change (Romdenh-Romluc, 2011, p. 150). In the study family members describe how their loved one’s behaviour during delirium was so different to what they expected and how turning away was lived and felt.

Merleau-Ponty’s (1945/2002) views on perceiving another person’s body align with Sartre’s (1943/2003) conceptualisation of the body as my being-there-for-others and the body-for-others. The body-for-others is the manifestation of my body when apprehending the other person’s body from my point of view (Stewart, 1998). In this manifestation Sartre (1943/2003) argues that the way in which another person’s body appears to me and my body appears to them are the same manifestation; “the other is not only the one whom I see but the one who sees me [sic]” (p. 252). Unlike Merleau-Ponty (1945/2002), Sartre (1943/2003) argues that in apprehending another person’s body my consciousness is of their body as a separate object to me; “others are the
Other, that is the self which is not myself” (p. 252). As I look at another person, my objectifying gaze makes them become aware that their body as looked at and regarded as an object by my consciousness (Stewart, 1998); they experience their body’s objectness through my outside perspective (Sartre, 1943/2003, p. 276). For Sartre (1943/2003, p. 279/287), the other person’s conscious awareness of me as an object in the world is a look that sees me as a person of a particular sort, a revelation of myself as a unique object for them. The other person knows what I am and in a way that I can never know myself; from the outside (Sartre, 1943/2003, p. 222). In Sartre’s (1943/2003) philosophy the body as being-there-for-others is the manifestation of my body in which I am able to identify the other person’s body with my own and am able to think that my body is for them what theirs is for me (Stewart, 1998). Recognising the impact of the other person’s look Sartre says “I exist for myself as a body known by the Other” (1943/2003, p. 375).

Sartre (1943/2003) also regards human relationships as bilateral and circular in nature as the person I look at is also capable of the look-back-at-me (p. 363). However, unlike Merleau-Ponty, Sartre (1943/2003) argues that my body as lived from the inside (being-for-itself) and my body as object (being-in-itself) cannot be experienced simultaneously. In his view either my body is an object or else it is subject and the vantage point by which things are revealed to me (Sartre, 1943/2003, p. 328). Sartre’s (1943/2003) notion of look therefore leaves little room for the genuine intersubjectivity argued by Merleau-Ponty (1945/2002) and described earlier.

Existential phenomenology argues that embodiment, as previously described by Sartre (1943/2003) and Merleau-Ponty (1945/2002), is missing from scientific views of the world. Adopting a phenomenological view in this study therefore required consideration of embodied intersubjective experience of things in a social world. In a context where delirium in older people is mainly considered from a biological and positivist perspective, one where the body of the older person is viewed from the outside and as an impaired object, turning to family member experiences of delirium drew attention to delirium as a different outside yet embodied experience and invited reflection on its lived subjective meaning for people other than older people themselves. Perceiving and knowing another person from the outside, as described by Sartre (1943/2003) and Merleau-Ponty (1945/2002), was therefore an important notion when exploring and interpreting the experiences of family members in the study. Grasping the distinction between the objective and phenomenal body, or outside and inside perspectives, was central to phenomenologically questioning and understanding family member experiences as embodied experiences within a social world.
Searching for the meaning of family member experiences also called for an understanding of how, from the phenomenological perspective, family members are able to know loved one’s intimately and how these understandings become the basis for who they expect to encounter now and in the future. Based on the intersubjectivity described by philosophers such as Merleau-Ponty (1945/2002), existential phenomenology argues that empathy is the intersubjective mode through which the other person becomes accessible to me (Moustakas, 1994). Through this characteristic of intentionality I experience a thereness-for-me-of-others (Moustakas, 1994, p. 37) through my look (Sartre, 1943/2003) or gaze (Merleau-Ponty, 1945/2002) at them. The world’s meaning to the other person is accessible to me because I perceive the other person as a subject, revealing themselves to me directly as not-a-thing (Luijpen & Koren, 1969/2010, p. 153/155). They are a subject like me and they are given-to-me directly by their look, gestures, speech and attitude, all of which are always theirs (Luijpen & Koren, 1969/2010, p. 155), such that they are in-person for me (Luijpen & Koren, 1969/2010, p. 36). This argument is based on the view that the other as a subject is primordially given-to-me (Luijpen & Koren, 1969/2010, p. 155/156), and suggests the other person is present to me in a special way; as a person, whose bodily gestures and actions are expressive of who they are and their state of mind (Luijpen & Koren, 1969/2010, p. 158). Existentially conscious-being-in-the-world, or being an in-person (Luijpen & Koren, 1969/2010, p. 36) defines life and the loss of these qualities defines death (Luijpen & Koren, 1969/2010, p. 36), albeit usually an end to both my subjective and objective existence. Death is therefore a complete withdrawal from the world, the end to my being human and to my subjective and objective existence, depriving my life of all meaning for me; “I am now what I am, a thing” (Luijpen & Koren, 1969/2010, p. 166).

In Chapter 7: Discussion and Conclusion I show the taken-for-granted basis through which family members in this study expected to encounter their loved one during delirium, and how family member experiences reveal their intentional conscious awareness of the corporeal presence of their loved one, including how they are different to expected or not who they are meant to be. Their loved one’s corporeal presence becoming the-other and an object of scrutiny, characterised by what Sartre (1943/2003) called magical animistic qualities. Otherness was a quality which was incongruous with family member taken-for-granted understandings of their older loved one and their loved one’s expected thisness (Sartre, 1943/2003). To expect (Sartre, 1943/2003) another person to appear in a particular way and to experience lack and absence (Sartre, 1943/2003) is described in more detail later in this chapter.
To be Human is to be Situated in the World

Sartre (1943/2003) and Merleau-Ponty’s (1945/2002) philosophies take the view that human existence is understood as the unity and reciprocity of subject and the world (Luijpen & Koren, 1969/2010, p. 51). Being-in-the-world, a term attributed to Husserl and later Heidegger, characterises human existence (Luijpen & Koren, 1969/2010). As expressed by Merleau-Ponty (1945/2002), “the world is not what I think but what I live through. I am open to the world, I have no doubt that I am in communication with it, but I do not possess it; it is inexhaustible. ‘There is a world’, or rather: ‘There is the world’.” (pp. xviii-xix). This means that my bodily consciousness involves me in the world so that the world is lived in everyday life as uniquely encountered by me (Luijpen & Koren, 1969/2010, p. 36).

As beings-in-the-world we act in the world before we contemplate it, making us fundamentally engaged or anchored in the world (Luijpen & Koren, 1969/2010; Macann, 1993). In addition, other people in the world invite us to reciprocate and participate in the world through their behaviour and speech (Luijpen & Koren, 1969/2010, p. 150). Also some things in the world point to other people and to their involvement in the world (Luijpen & Koren, 1969/2010, p. 36); my husband’s bed points to “his” body curled in sleep; a straight jacket points to “my friend’s” loss of bodily control and their contained body posture when mentally unwell. Merleau-Ponty (1945/2002) refers to these things as cultural objects, a notion discussed later in this chapter. These ways of being-in-the-world diverge from objectivity as the fundamental manner of our being.

As an existential phenomenologist Sartre (1943/2003) insists that consciousness is necessarily directed to the world; he says “the concrete is man within the world” (Sartre, 1943/2003, p. 27). He maintains that first and foremost our intentional directedness, our experience, is of the world, or our situation. In his view our being is always “in situation”; “the body is not distinct from the situation (…) to exist and to be situated are one and the same” (Sartre, 1943/2003, p. 333). Hence although Sartre does not embrace Husserl’s lebenswelt or life-world as terms, his philosophy accepts human existence as embedded in the lifeworld. In his view embodiment in the world also involves knowing other people as their body is always given-to-me in a situation or a meaningful context, a situation which in itself has been determined by the other’s bodily actions and expressions (Sartre, 1943/2003).
Like Sartre (1943/2003), Merleau-Ponty (1945/2002) adopts being-in-the-world to describe the situatedness of being human. As expressed by Merleau-Ponty “I am given, that is, I find myself already situated and involved in a physical and social world-I am given to myself, which means that this situation is never hidden from me” (1945/2002, p. 419). Merleau-Ponty (1945/2002) argues that perception and embodiment are constitutive elements of our being-in-the-world that our perspective on the world is unique. He says “our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system” (Merleau-Ponty, 1945/2002, p. 235). At times Merleau-Ponty refers to Husserl’s lebenswelt to describe our world and at others to the phenomenal field; the world that is presented in experience, containing both things of the world and the body of the perceiver (Merleau-Ponty, 1945/2002). In his view it is the phenomenal field that is human experience and hence it is considered as an object for phenomenological investigation (Merleau-Ponty, 1945/2002).

Merleau-Ponty (1945/2002, p. 81) argues that perception presents the world from a particular point in space and time, and I experience myself as located at that space and time in a way which is different to time and space as merely material or objective things. My perception of the world centres on my experience; “I” am here, and other objects are where they are in relation to “my” here (Matthews, 2010). Near and far depend on where I am. What I perceive is big if I cannot take it all in at once, and small if I have to move closer to get a better look (Merleau-Ponty, 1945/2002, p. 353). In the same way “now” is what I presently experience (Matthews, 2010). Past and future are defined by my present which is in turn determined by my experience of “now” (Matthews, 2010). Merleau-Ponty argues furthermore that I carry time sedimented in my body, in my very subjective existence, making time at the heart of my being-in-the-world (Matthews, 2010). My situation now is precisely what it is because of the context that my past provides (Matthews, 2010). Sartre is influenced by both Husserl’s and Heidegger’s phenomenology of time and, like Merleau-Ponty, sees the past, present and future as a temporal whole which is connected to bodily manifestations (Priest, 2001, p. 164). Though Sartre sees the past as belonging to the in-itself, the present to the free for-itself and the future to pure possibility, they remain someone’s (Priest, 2001).

The social dimension of Merleau-Ponty’s (1945/2002, p. 405) human world includes what he calls cultural objects and behavioural sediments. He argues that cultural objects are things in the world that are used or produced by people (Romdenh-Romluc, 2011). Hence these objects do not appear to me as other natural objects do, like a tree
for example. When perceived I immediately see the cultural object as connected to another person and some form of human behaviour; “Each of these objects is moulded to the human action which it serves. Each one spreads round it an atmosphere of humanity” (Merleau-Ponty, 1945/2002, p. 405). Behavioural sediments appear as cultural objects deposited in my world as *things* and, no matter how much linear time has passed, give me a sense of past people in my world (Romdenh-Romluc, 2011). Though each perception in itself does not provide much detail about who the other person is, the object is distinctively human and gives me a sense of another person (Romdenh-Romluc, 2011). Using the examples of a can in the forest, human footprints in the sand on a beach and entering an evacuated home, Merleau-Ponty (1945/2002) illustrates how the intensity of sensing the other person varies and may or may not be associated with highly determinate human activities. In contrast to experiencing the presence of another person, to see *cultural objects* is to feel the presence of other people without them actually being present (Romdenh-Romluc, 2011). Merleau-Ponty wrote:

In the cultural object, I feel the close presence of others beneath a veil of anonymity. Someone uses the pipe for smoking, the spoon for eating, the bell for summoning, and it is through the perception of a human act on another person that the perception of a cultural world could be verified. (1945/2002, p. 405)

Importantly Merleau-Ponty (1945/2002, p. 406) argues that I understand the *behavioural sediments* of *cultural objects* by *likeness* with my own behaviour, and its significance to me. As expressed by Merleau-Ponty:

I see a certain use made by other men of the implements which surround me, that I interpret their behaviour by analogy with my own, and through my inner experience, which teaches me the significance and intention of perceived gestures (…) the actions of other are (…) always understood through my own. (1945/2002, p. 406)

In his view the primary *cultural object* is the body of another person; “the very first of all cultural objects, and the one by which all the rest exist, is the body of the other person as the vehicle of a form of behaviour” (Merleau-Ponty, 1945/2002, p. 406).
Existence as *embodied-subjectivity-in-the-world* acknowledges that, through the body, we are tied to personal, historical and cultural contexts, and that we are comprehensible only in our worldly contexts (Luijpen & Koren, 1969/2010, p. 36; Oiler Boyd, 2001, p. 37/97). Embodied we live in a particular culture, at a particular time and in a particular place, and within these contexts the meaning of experiences can be understood (Luijpen & Koren, 1969/2010, p. 36). The world is however so much a part of everyday experiences that it is easy to take it for granted and dismiss how much of our subjective world knowledge is unspoken (Fjelland & Gjengedal, 1994).

Research guided by existential phenomenology appreciates the unique contribution the world makes to perception, experience and meaning. Based on the philosophies of Sartre (1943/2003) and Merleau-Ponty (1945/2002) family member experiences in the study were viewed as already situated in a social and physical world; as occurring at particular times, in particular places and within relationships with other people. Family members in the study described encountering their loved one when visiting health care contexts such as residential aged care and acute hospital wards, and within relationships which were part of family and health care networks. Family members described sharing a past with their loved one, a “now” and an uncertain future together. For some family members their experience was short, for others delirium lingered and their experience was drawn out. Aspects of their situation were unable to be changed, such as their gender, age, country of birth, the older person and their delirium. These aspects represented the concrete or the facticity of their experience. The situation of each family member in this study was therefore viewed as integral to family member experiences and needed to be gleaned in order to understand the meaning of being with their older loved one during delirium.

As shown in Chapter 6: Findings, when family members were with their older loved one during delirium, they are with them in a way which reflects their past and how they continue to be connected to one another. Their lives had been and continued to be interwoven and an intimate understanding of one another continued to unfold. Past experiences of illness and health care were recalled into the “now”, impacting on what it was like to be with their loved one during delirium and, for some women, when delirium reoccurred. When past experiences involved mental illness and use of straight jackets, Merleau-Ponty’s (1945/2002) description of *cultural objects* and their meaning was particularly helpful in understanding the situatedness of their experiences and what family members were describing.
Searching for Meaning

The focus of research guided by phenomenology is not on casual explanations but the development of descriptions that represent an interpretation of the essence or the meaning of the experiences explored, so that what it is to be human and involved in the world can be better understood (Creswell, 2007; Kvale & Brinkmann, 2009; Moustakas, 1994; Munhall, 2007). For research guided by interpretive phenomenology, experience is viewed as the knowledge people have of the phenomenon being considered, knowledge they have acquired because they have experienced the phenomenon in their everyday human activities and within their own context (Taylor, Kermode, & Roberts, 2006). For Sartre (1943/2003) the world we live in is one of significance with inherent meanings. The appearance of things to our consciousness is indicative of an aspect of itself, manifesting its existence and revealing its essence. For Sartre (1943/2003) the essence of things are not located in the things of the appearance. Rather it is the meaning of the thing which is given to me through appearance (Priest, 2001). The appearance thus is both the essence and reveals the essence; “what it is, it is absolutely, for it reveals itself as it is” (Sartre, 1943/2003, p. 2). Meaning is hence not imposed on things by me, nor does its appearance hide its meaning; rather things reveal their meaning to me when I encounter them (Sartre, 1943/2003, p. 2). Sartre (1943/2003, p. 8) therefore views the truth of what is experienced as existing for me and self-evident from what is lived through rather than through what is thought. Things can be studied and described as they are “absolutely indicative of itself” (Sartre, 1943/2003, p. 2).

Following a similar path Merleau-Ponty (1945/2002) argues that being-in-the-world condemns us to meaning because we are engaged with it, primarily in unreflective ways but also in reflective ways. Like Sartre (1943/2003), Merleau-Ponty (1945/2002) says that the meanings which things have for me are not given by me or by my thoughts. Rather my body is like a vehicle and through it meaning is discovered by me in things themselves, so making my being-in-the-world like engaging in a dialogue with the world (Merleau-Ponty, 1945/2002, p. 373). In Merleau-Ponty’s (1945/2002) view consciousness is tied to perception and experience, and allows the meaning of what appears to consciousness to be sought using a phenomenological way of thinking:

The phenomenological world is not the bringing to explicit expression of a pre-existing being, but the laying down of being. Philosophy is not the reflection of a pre-existing truth, but, like
Merleau-Ponty (1945/2002) describes phenomenology as the study of essences, and like Sartre (1943/2003), essences as already present in the intentional relationship between things and us rather than being added. Merleau-Ponty (1962, p.xx) also argues that the intention needs to be grasped, including the properties and the unique mode of existing, in order to understand. Merleau-Ponty (1945/2002) says:

The thing is inseparable from a person perceiving it, and can never be actually in itself because its articulations are those of our very existence, and because it stands at the other end of our gaze or at the terminus of a sensory exploration which invests it with humanity. (p. 373)

By embracing a phenomenological approach for the study I did not just want to know what human experience was like, i.e. its facticity. I wanted to understand the meaning of this experience. So I explored and described the lived meanings of family member experiences with older loved ones during delirium. The meanings of being with loved ones were uncovered through being exposed to the qualities of their experiences, thoughtfully attending to their descriptions of being-in-the-world, and through careful attention to my prior understandings. Integral to the phenomenological approach was overcoming, as much as possible, my subjective and private feelings, preferences or expectations, including theories or scientific conceptions which influence how things are seen (Merleau-Ponty, 1945/2002; van Manen, 1990). Under scrutiny was my natural attitude or natural standpoint, the unchallenged, ingrained and relied upon understandings of the world which give my every day experiences of the world some continuity, predictability and feelings of security (Daly, 2007; Munhall, 2007). Our natural attitude creates meanings which are grounded in unchallenged and ingrained understandings of the world, sometimes handed down through generations (Daly, 2007; Munhall, 2007). It also forms the basis for the way we rely and take our understandings of other people and the world for granted. Of particular importance to Merleau-Ponty is suspending what he argues is our flawed objective thought, or the ordinary everyday conceptual framework used to think about things (Matthews, 2010). In Merleau-Ponty’s (1945/2002) view, objective thought is a problem because it cannot account for embodied perception and leads us to direct our focus onto things as objects of experience, for example delirium as a medical condition, rather than to the human experience itself (Romdenh-Romluc, 2011). However, the natural attitude is not
fixed, allowing us to choose to take another standpoint, including a phenomenological attitude, so opening up experience and understanding from another perspective (Stewart & Mickunas, 1974, p. 24/25).

**Un-knowing the World and Constitutionality**

When engaged with the world, phenomenologists argue we adopt a particular attitude filled with relied-upon understandings which, without needing resynthesis, keep the world familiar and predictable, and creates feelings of security. Attempts to un-know these prior understandings of the world has origins in descriptive phenomenology (Moustakas, 1994; Stewart & Mickunas, 1974), and is often referred to as *phenomenological reduction* or *bracketing prior understandings*. In its original form *bracketing* was an attempt to purify *consciousness* so that the pure essence of human experience could be seen (Stewart & Mickunas, 1974). However, philosophers from the interpretive phenomenological movement, including Merleau-Ponty (1945/2002, p. xv) and Sartre (1943/2003), have argued against this tenet. In their view *bracketing* dislocates conscious states from the world and suggests a way of thinking which, because we first of all exist in the world, is impossible to achieve. As Merleau-Ponty wrote “the most important lesson which the reduction teaches us is the impossibility of a complete reduction” (Merleau-Ponty, 1945/2002, p. xv). This line of argument reveals that interpretive and existential phenomenology see the complete suspension of the natural attitude as unachievable and the presence of some prior understandings to be a continuous possibility as our existence affects the conceptualisation of meaning (Grbich, 2007, p. 91). They prefer instead to acknowledge the possibility of an interpretive foreground and the role it plays (Benner, 1994b). Although not subscribing to bracketing as such, existential phenomenology argues that prior knowledge of the world, including scientific knowledge, should be put *out-of-play* as much as is possible and emphasise openness, exploration and acknowledgement of the natural attitude (Benner, 1994b; Merleau-Ponty, 1945/2002, p. xiv; Munhall, 2007).

Adopting an *out-of-play* (Merleau-Ponty, 1945/2002, p. xiv) stance is aimed at seeing the world and the experiences of other people afresh, interpreting their experiences anew and away from conceptualisations and categorisations (Merleau-Ponty, 1945/2002; Moustakas, 1994; van Manen, 1990). Un-noticed or *taken-for-granted* ways of knowing the world create a familiar acceptance of the world and what it is like to be human (Merleau-Ponty, 1945/2002, p. xv). They act as a foreground or filter through which the world is understood, and through which the perspective of others can be distorted or hidden (Hamill & Sinclair, 2010; van Manen, 1990). As an *out-of-play*
stance recognises that the researcher’s world is value laden (Creswell, 2007), that past knowledge influences current ways of understanding and that knowledge is created from a particular perspective, an open, receptive naivety of listening was called for (Merleau-Ponty, 1945/2002; van Manen, 1990). The researcher’s perspective therefore needed to be opened and broken so that the world and experiences for other people could be unveiled and grasped (Merleau-Ponty, 1945/2002; Munhall, 2007; van Manen, 1990).

For a researcher the process of uncovering, understanding and becoming aware of their own natural attitude involves continuous reflection and has been referred to as unknowing and de-centreing (Munhall, 1993). Inherent in coming to understand your own natural attitude and to see the world through a different perspective is an attempt to shift into what phenomenologists call the phenomenological attitude, one that disconnects from relied-upon understandings of the world (Merleau-Ponty, 1945/2002; Stewart & Mickunas, 1974, p. 26). Recognising and making explicit personal beliefs, common sense and scientific pre-understandings and assumptions are therefore an important part of bringing personal perspectives to awareness when applying phenomenology in research (Merleau-Ponty, 1945/2002, p. xv; van Manen, 1990). Merleau-Ponty’s (1945/2002) use of art illustrates one way of thoughtfully and attentively “re-learning to look at the world” (p. xiii), a way similar to the use of additional data sources in this study (see Chapter 4: Study Design and Methods).

During this study the purpose of developing researcher self-awareness and adopting an out-of-play orientation was to enhance my ability to see the phenomenon anew rather than interpreting the phenomenon through pre-existing biases, filters or conceptualisations. Participants and their experiential descriptions were approached from the humble but attentive stance of a perpetual learner, trying to not know or anticipate what family members would describe as their experience but wanting to know their perspective. The task was to draw out pointers to phenomenon and to shine new unfiltered light on what is disclosed. To assist me to achieve this attitude I used images and metaphors to challenge my natural attitude, to point me to the perspective of family members and to help me to hear what they were saying (see Chapter 4: Study Design and Methods for a full description of strategies used). The attitude needed was therefore not one that denied my own existence or adopted a privileged or nullified point of view. Rather an attitude that broke with the familiar, which found and recognised blind spots, which looked for personal sway and attempted to stand in the shoes of another and to see the world from a new perspective.
To enquire into the meaning of experiences for family members using existential phenomenology also required an interest and concern for how family members integrate and cope with puzzling and distressing life experiences. How each family member uniquely perceived and was aware of their loved one during delirium was of interest; their individual subjective reality rather than my perspective, objective truth or the facts of delirium. Phenomenology argues that adopting a phenomenological view requires an abandonment of physical views of the body and consideration of embodied experience of things in the world. In a context where delirium in older people is mainly considered from a biological and positivist perspective in which the body is impaired, returning to experiences of family members during delirium offered the opportunity consider delirium as an embodied experience and to pause and reflect on its lived subjective meaning.

Together with the process of unknowing and putting out-of-play prior understandings, interpretive phenomenology adopts Heidegger’s notion of co-constitutionality (Lopez & Willis, 2004). Co-constitutionality refers to researcher and participant intersubjectivity, and to the blending of researcher and participant perspectives during the process of interpreting and understanding experiences (Lopez & Willis, 2004). Qualitative research approaches, including existential phenomenology, take conversations to be filled with meanings portrayed through participants’ dialogue (Yardley, 2000). By listening to family members and asking questions I contributed to the dialogue; remaining neutral during interactions, or when dwelling on family member experiences, was impossible. The final interpretations of family member experiences are therefore viewed as co-created meanings. In addition, the meanings communicated in the study findings cannot claim to be the total meaning. Benner (1994b) argues that we can never completely understand the experiences of others “because human beings and worlds are not objects and cannot be frozen in time or explicated fully” (p. 100). The family members in the study are individuals who brought to the study their own perspectives and while they shared rich descriptions, their experience can never be fully disclosed to others in the world.

**Expectation, Lack and Existential Absence**

Sartre’s philosophical works are extensive, however, during the study it was his consideration and explication of expect, lack and absence (Sartre, 1943/2003) that resonated with family member descriptions and helped me to understand their meaning. While working with the data I was struck by family member descriptions of being with someone familiar and then suddenly unfamiliar or foreign. This led me to
stop and contemplate their experiences and consider what they were saying, and over
time, contemplate likeness with the notions of expect, lack and absence (Sartre,
1943/2003). As all the descriptions of family members were progressively explored it
emerged that the way the body of family members was manifest to, and in the world
during delirium, was with existential absence (Sartre, 1943/2003).

In Being and Nothingness (Sartre, 1943/2003, pp. 33-35), Sartre describes the notion
of absence by exploring a situation where he has an appointment with Pierre in a café.
Sartre arrives late and enters the café looking for Pierre, an action which organises the
café to be the ground for Pierre’s appearance to Sartre; the ground on which Pierre is
given as about to appear (Cox, 2007). In Sartre’s experience the café is seen only “in
addition” and with purely marginal attention, a disappearance to his perceptual
background as he looks at the different patrons searching for the face of Pierre; the
patron’s faces falling to the background “precisely because they ‘are not’ the face of
Pierre” (Sartre, 1943/2003, p. 34). Thus the café falls to the ground as a necessary
condition for the appearance of Pierre as a figure of Sartre’s perception. Should he
have found Pierre the whole café would organise itself in his perception around Pierre’s
presence (Cox, 2007). For Sartre however, Pierre is not present and figure-
nothingness pervades his experience (Cox, 2007). Sartre explains that Pierre’s
absence supposes an original relation between himself and the café that establishes
Pierre’s absence and allows his negative judgement; that “Pierre is not here” (Sartre,
1943/2003, p. 34). It is Sartre’s expectation of Pierre in that café that has “caused the
absence of Pierre to happen as a real event” (Sartre, 1943/2003, p. 34). For Sartre,
Pierre’s non-being is not created by the negative judgement itself, rather Pierre’s non-
being in the situation is the condition of the negative judgement (Cox, 2007). As Sartre
(1943/2003) says “Pierre’s absence haunts this café” (p. 34) and is real and not just a
psychological state; nothingness is really experienced. Pierre is elsewhere.

Though comparatively simple in fact, Sartre’s experience is complex, involving negative
judgement, conscious intentional awareness, embodied figure/ground perception and
non-appearance. Through his description he considers how an experience in the world
is characterised by lack and the absence of an expected friend (Cox, 2007). In doing
so, Sartre illustrates his argument relating to the structure of the for-itself (the
conscious free self); that all situations are interrupted according to their personal
significance, often according to desire, hopes and expectations (Cox, 2007).
Furthermore every situation we encounter is understood as presently lacking
something for us (Sartre, 1943/2003, p. 110). In Sartre’s example, it is his expectation
that Pierre would be in the café and the lack of Pierre. To expect a person is described
by Sartre (1943/2003) as a way in which we encounter and anticipate the world for us. When what appears to us in the world falls short of our expectations, our world lacks something for us (Cox, 2007); absence is lived specifically by someone.

In the study I considered what family members desired, hoped for and expected when they were with their older loved one during delirium. I reflected on how their expectations lead them to perceive something to be missing or lacking in their situation. As the experience of lack is, however, not merely a thought or facticity, I contemplated what it was like for family members to experience lack and absence (Sartre, 1943/2003) though their loved one’s corporeal presence remained in their situation. As discussed more fully in the following chapter, their loved one’s taken-for-granted presence as the-other-in-the-world was suddenly gone and replaced by something different. Expectation of their loved one’s co-presence and experiencing of their lack causes an absence to be lived as a real event by family members. Importantly Sartre (1943/2003, p. 110) emphasises that the situation itself is not lacking. Rather, something is lacking in the person’s experience of the situation, revealing that consciousness is predisposed to find something lacking in the world (Sartre, 1943/2003), and that people with different perspectives on the situation may not experience the same lack and absence. As Sartre stays:

[Lack] appears in the world only with the upsurge of human reality (…) A lack pre-supposes a trinity: that which is missing or “the lacking”, that which misses what is lacking or “the existing”, and a totality which has been broken by the lacking and which would be restored by a synthesis of “the lacking” and “the existing”. (…) The being which is released to the intuition of human reality is always that to which some thing is lacking. (1943/2003, p. 110)

Sartre also explores the notion of lack through his experience of the moon (Sartre, 1943/2003, p. 110). He explains that though looking at a crescent moon, the partial moon as an object does not lack anything. It is what it is. However, for the person looking up, a crescent moon is understood as a partial appearance or a lack of the full moon. The crescent moon is understood by consciousness as partial by virtue of what is lacking (Cox, 2007). For family members, their loved one has a partial appearance in their situation; they lack (Sartre, 1943/2003) the spirit (Merleau-Ponty, 1945/2002) or person they know, love and trust whilst having a corporeal presence; they are no longer a familiar whole for family members. At the same time other people sharing the
situation with family members may not expect the familiar loved one nor experience *lack* and *absence* (Sartre, 1943/2003). As discussed more fully in the last chapter, for health care staff, the older person is likely to have a corporeal presence and be who they are “now” rather than lacking in familiarity; they are whole.

**Review and Summary**

This chapter began with a justification for adopting existential phenomenology as the guiding approach to answer the research question posed for the study. In this justification a “fit” was noted between existential phenomenology and the research question, the maturity of the concept and my personal interest and concern for family members who experience being with their older loved one during delirium. As the chapter progressed I discussed existential phenomenology as the philosophical underpinning to the study. Particular attention was given to the philosophical works of Sartre (1943/2003) and Merleau-Ponty (1945/2002) when discussing the phenomenological tenets rated to *consciousness, intentionality, perception, embodiment, the lived world* and the meaning of experience. I identified existential phenomenology as being concerned with moving away from empirical explorations of the world and towards a perspective where human *conscious awareness* of things in the world has implicit meaning. Also that it is concerned with considering and describing situated human experience and elucidating its meaning, often meanings which are hidden or embedded in everyday experience of existence. In this discussion I explained the relevance of arguments provided by existential phenomenology to the research question, to the people of interest to the study, and to health care. Also disclosed through discussion of the notions of *expect, lack* and *absence* (1943/2003) is the interpretive connection between existential phenomenology and the women’s experiences during their older loved one’s delirium. The discussion in this chapter has hence laid open the theoretical paradigm and the stance taken in completing the study.

At the beginning of the Chapter I returned to my argument that health care staff can only truly help family members if they understand the perspectives of family members themselves (Cohen et al., 2000), and that with improved understanding health care staff have the opportunity to appropriately encourage family member participation in care and to provide sensitive and compassionate interventions that support family members through their experience. This supports the argument that the findings of the study, those based on existential phenomenology, will add to the current limited knowledge about family member experiences during their older loved one’s delirium.
In the next chapter I turn to describing how existential phenomenology guided study design and the methods employed, and to how the study was progressed to explore family member experiences during delirium.
CHAPTER 4: STUDY DESIGN AND METHODS
Chapter Introduction

This chapter presents the study’s design and methods, revealing how existential phenomenology, as described in the previous chapter, has been used to explore the experiences of family members during an older person’s delirium. Using an adaptation of Van Manen (1990) and Munhall’s (2007) inquiry activities as a framework, the study design and the methods employed are described. Evident in these descriptions is how my curiosity about the experience family members evolved, along with the difficulties and demands encountered in completing the study. A need for flexibility in coping with the emergent nature of qualitative research is illustrated.

Initially the discussion focuses on the approach taken to use existential phenomenology to answer the research question and trustworthiness considerations. Following this, how I came to research the phenomenon of interest, the aim of the study, and my assumptions and pre-understandings are described. How family member experiences were investigated, lived experience materials used, and how the data were analysed and interpreted is then described. Included is a discussion of the difficulties encountered in accessing family members as participants, and initial and evolving ethical considerations central to conducting the study.

Trustworthiness and Applying Existential Phenomenology

Three concerns were central in choosing, enacting and modifying the study's design and methods. The first was ensuring that the design and the methods employed would enable the research question to be answered, secondly that the way used would provide insights that were trustworthy, and finally that the design and methods were consistent with a phenomenological orientation to research.

Trustworthiness

Establishing trustworthiness in phenomenological and other qualitative research approaches has received considerable attention and debate in the literature (Caelli, 2000; Crotty, 1996; Koch, 1994, 1996; Munhall, 2007). This debate has largely centred on a need for criteria that reflect the nature of qualitative research approaches rather than measuring trustworthiness using quantitative rules for rigour. Taking a proactive approach, Guba and Lincoln’s (Guba & Lincoln, 1982; Lincoln & Guba, 1985, 1986) criteria for assessing and guiding trustworthiness in qualitative research were consulted when making decisions about design and the methods to employ. This approach
evidences a position which considered quantitative criteria for rigour to be inappropriate when employing qualitative methodologies, and a commitment to using an approach to study trustworthiness that was grounded in the qualitative paradigm.

Guba and Lincoln’s (Guba & Lincoln, 1982; Lincoln & Guba, 1985, 1986) criteria for trustworthiness largely focus on methodological aspects of the study, and include the criteria of credibility, transferability, dependability and conformability. Credibility speaks to the truth value of the research and refers to the fit between the participants’ views and the descriptions and interpretations presented by the researcher (Guba, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1986). Transferability speaks to applicability, and establishes the extent to which the meanings and interpretations of the study are relevant to and can fit into contexts or situations similar to those in the study. It rests on the depth of subjective meaning and the richness of the described contextual picture rather than breadth or sample characteristics. Transferability is, however, relative and dependent upon the degree to which readers of the study view the findings as matching, applicable and meaningful for their interests (Guba, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1986). Dependability considers consistency (Guba, 1981) and establishes if another researcher can follow design and methodological decisions (Sandelowski, 1986). Sandelowski (1986) suggests that although the emergent nature of qualitative research is known, another researcher should be able to arrive at a comparable interpretation given a description of the participant data, the context, the decisions and perspective. Finally, confirmability considers neutrality and refers to the researcher’s involvement in the interpretation of data and how well the study’s interpretations and findings are linked to participant data (Lincoln & Guba, 1986). As noted in the previous chapter, in interpretative phenomenology it is acknowledged that the researcher has a perspective and is involved in the interpretation of meaning from the data (Koch, 1996). The position of the researcher therefore needs to be explored and examined, then acknowledged and considered as part of the interpretive process and the findings (Koch, 1996; Munhall, 2007; van Manen, 1990). When the participants’ experiences have clearly remained at the core of interpretation and when the interpretative process can be followed by other people, confirmability becomes apparent (Guba, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1986). In the following discussion aspects of the study which influence trustworthiness are highlighted and the decision trail is laid open for examination and scrutiny.
Phenomenological Orientation

Another concern in relation to the study was the creation and maintenance of a phenomenological orientation when exploring the experiences of family members during a loved one’s delirium. As described in the previous chapter, existential phenomenology concerns itself with understanding human experiences of being-in-the-world and with questioning the way the world is experienced in our everyday mode of existence (Merleau-Ponty, 1945/2002; van Manen, 1990). It requires exploration of the intentional relationships between people and the world and a search for the meaning of everyday existence (Finlay, 2009; van Manen, 1990). It also values the complexity and individual nature of lived experiences, personal subjective insights and the situated person (van Manen, 1990).

In adopting existential phenomenology I was concerned with orienting to human experiences of delirium, collecting rich lived experience descriptions and exploring the experiences of family members during their loved one’s delirium in what van Manen (1990) describes as “all its modalities and aspects” (p. 32). The data sought were actual experiences of everyday life, situated at a particular time, in relation with others, and within a context (van Manen, 1990). The design and methods employed when translating phenomenology, as a qualitative research approach, minimised my distance from the family members, promoted engagement over time and knowledge of their context.

Like empirical research, research guided by existential phenomenology uses systematic activities to achieve its intent (van Manen, 1990). The strength of these activities lies in their focus on facilitating access to various lived experience materials, developing sensitivity to the uniqueness of each person and their situation, sustained engagement and reflective examination and interpretation (Munhall, 1994; van Manen, 1990). For this study the interconnected inquiry activities suggested by Munhall (2007) and van Manen (1990), as outlined below, were explored and later adapted as a guiding framework to achieve the study’s intent. This adaptation complemented the aim of the study, my interest in working with more than one source of lived experience material and drew on the strengths of both approaches. Importantly it provided a design and methods which were consistent with phenomenology as philosophy. In addition, Munhall’s (1993, 1994, 2007) health and nursing discourse challenged and enhanced contextual understandings, helping me to understand how, as a nurse and researcher, I could remain true to the phenomenological perspective while conducting the study.
The following interconnected inquiry activities formed a framework for the study’s design and methods, and were used to guide the study to completion:

1. Focusing on the phenomenon for the study;
2. Investigating experience as it is lived;
3. Analysis of interpretive interaction;
4. Writing the phenomenological narrative;
5. Writing a narrative on the meaning of the study.

(Munhall, 2007; van Manen, 1990)

The following sections describe how each of these inquiry activities were employed, revealing how my interest and curiosity were directed towards the nature and meaning of family member experiences during delirium. The description is however a sequential account bound by language and text, possibly constraining the portrayal of the study’s emergent and thoughtful nature. Adopting a phenomenological orientation required a flexible, interconnected and organic style rather than rigid linear steps. Much thinking, questioning and adjustment was needed to locate family members with experience of delirium, to collect their experiential descriptions and to come to understand their meaning. Going back and forth between experiential descriptions and each participant’s life context became the norm and was, at times, sad or surprisingly inspiring. Important throughout was having a strong orientation and commitment to revealing the meaning of family member experiences during their loved one’s delirium without referencing existing theories, conceptualisations, pre-understandings, contextual limitations or speculations.

**Focusing on the Phenomenon for the Study**

In phenomenological research, van Manen (1990) and Munhall (2007) argue that time is needed to consider the phenomenon to be explored. I was aware that delirium had been on my nurse’s mind for some time, perhaps because of witnessing behaviour that was bizarre and violent when caring for people during delirium. Or perhaps because it aroused fears that I could not help my older patients or their family members and worried about their futures. Perhaps it became a more personal and urgent concern when I was a family member caring for my mother when she was delirious; the way I experienced my mother’s behaviour, the worries I had and the staff’s reactions to what was going on at the time (see Chapter 1: Study Introduction). It is also likely that my abiding concern about delirium came from listening to, and wondering about, the many and varied experiences of other people; experiences of nurses, acute care doctors,
general practitioners, residential aged care staff, family members, older people, neighbours and children. Each time delirium was raised I was drawn into asking what delirium was like for those involved rather than what was its cause or treatment. The more I thought about delirium, looked for experiences and talked about what delirium was like for other people, I found more questions and even greater interest. I began to appreciate the breadth of the phenomenon in everyday life, to question my own experiences and to explore possibilities for understanding delirium from each person’s unique perspective. I considered delirium and other experiences of acute or chronic confusion and questioned their connection and uniqueness. I pondered what it was like for the people involved rather than the condition itself; I wondered what they thought, what feelings were roused and what sense they made of what happens.

My curiosity initially settled on delirium in older people even though other people experience delirium when acutely and seriously ill. It is likely that this interest developed from a professional and ongoing passion for improving the care of older people. However, I found I was particularly interested in the experiences of family members who were present or cared for older people during delirium rather than the older person themselves or health care staff. The possibility that family members would be familiar with chronic confusion, or dementia, was raised as part of their experience and an interest in understanding how their experiences changed or stayed the same when delirium developed. At the time it seemed that family members had been forgotten by health care staff whose interest, some would argue understandably, was focused on the care of the older person. Shared stories from nurses and family members suggested that family members were used as care resources when the older person displayed disruptive behaviours and became uncontrollable or uncooperative. Some noticed that family members spent long periods with their older person or were reluctant to leave. Also motivating my interest were personal experiences as a family member and those as a community nurse working with carers in community care contexts. I was interested in helping to make sense of and voice family member experiences during delirium, a perspective rarely expressed in research literature (see Chapter 2: Literature Review) or, from my experience in clinical care contexts. I wanted to provide understandings that would support health care staff to be compassionate and sensitively support family members during their experiences of delirium and appropriately involve them in their older loved one’s care. Coming to this focus for the study improved awareness of my nursing and personal experiences, perspectives through which I understood delirium and through which I remained oriented during the study.
Aim of the Study

I began this study with the intent of increasing understanding of the experiences of family members when with their older loved one during delirium. I hoped to add fresh subjective insight to the field of knowledge about delirium in older people, a field currently dominated by empirical research with a biomedical orientation. As Maxine Greene, an American social philosopher says, I wanted to “break with the ‘cotton wool’, of habit, of mere routine, of automatism, to seek alternative ways of being” (1988, p. 2).

With an interest and focus on the phenomenon of older people in delirium and on family member experience, I aimed to explore what it was like for family members to be with their older loved one during delirium. As noted previously my interest was not in exploring this experience from the perspective of proxies such as health care professionals or the researcher. Reflecting an interest in the perspective of family members the research question asked “What is the lived experience of family members who are with an older person when the older person has delirium”? The related research questions were:

1. What do family members say about experiencing delirium in an older family member?
2. What are the thoughts, feelings and concerns of family members?
3. What impact do experiences of delirium have on family members?

In voicing the study’s aim and research questions I was mindful that I was seeking to explore and make sense of family member experiences during delirium and to retrospectively uncover their meaning (van Manen, 1990). The intent was to describe and interpret; to explore beyond the outward or factual nature of the experience to the inner experiences of thoughts, feelings, concerns, pleasures or pains; to develop a phenomenological text that, when read by others, would have authenticity and the potential to enhance understanding when caring and supporting family members during their older loved one’s delirium.

Assumptions and Pre-understandings

Integral to research guided by existential phenomenology is working to disclose the world in ways which reveal how it is experienced by people. This type of disclosure aims to see the world afresh and to interpret experiences anew, and is facilitated by being open, receptive and naive in listening (Merleau-Ponty, 1945/2002; Moustakas, 1994; van Manen, 1990). This stance, as described in the previous chapter, is known
as the phenomenological attitude and is one that recognises knowledge is created from a particular perspective. The un-noticed or taken-for-granted ways of knowing the world act as a foreground or filter through which the world is understood, and through which the perspective of others can be distorted, hindered or hidden (Hamill & Sinclair, 2010; van Manen, 1990). Acting like a filter or distortion, the researcher's perspective can therefore have pervasive influences on the way the world and the lived experiences of others are interpreted (Merleau-Ponty, 1945/2002; Munhall, 2007; van Manen, 1990).

Recognising and making explicit personal beliefs, common sense & scientific pre-understandings and assumptions are an important part of bringing personal perspectives to awareness (van Manen, 1990). The idea of then putting out-of-play personal perspectives so that a phenomenological attitude can be adopted is argued by Merleau-Ponty (1945/2002). As discussed in Chapter 3: Guiding Approach, Merleau-Ponty (1962) places particular importance on suspending what he considered objective thought, because in his view it tends to direct attention onto the objects of experience rather than to the experience itself. The attitude needed to progress the study was therefore one that broke with the familiar, which found and recognised blind spots, which attempted to stand in the shoes of family members and to see the world from their perspective.

Consistent with a phenomenological attitude I attempted to draw to my own attention, describe and question my perspective of the world. This was not a simple or brief undertaking. Regular discussion of all aspects of the study with my research supervisors exposed me to searching questions from experienced researchers and searched my biases, explored meanings and clarified the basis for my interpretive decisions. Openness to self-discovery was needed, along with a commitment to initial and continued reflection and questioning of my knowledge of the world. Although difficult and at first frustrating, the required thoughtful and reflective process facilitated access to pre-understandings by bringing them into conscious awareness. Once brought to light it became possible to question the influence of my perspective, and monitor its sway on the collection, analysis and interpretation of lived experience material. Ultimately this helped me to focus on and remain genuine to the perspective of family members in the study and their experience during delirium, rather than giving preference to scientific understandings or my own perspective, so helping to build study credibility and confirmability. Although it is not possible to list or describe all aspects of self-discovery and understanding achieved during the study, the following paragraphs share some main beliefs, assumptions or pre-understandings that were important to the way the study was designed and developed or to the interpretation of
lived experience material. They illustrate a commitment to family member experiences and perspectives, and to being open about how I saw the world.

Recognising Personal Understandings

Early in the study I believed that delirium was frequently experienced by older people when in residential aged care or hospital and that it was often an inevitable outcome of admission and acute illness and injury. I thought of delirium as a diagnosis or a medical condition and thought the term was solely located in health or medical discourses. From prior research experiences I thought that many older people developed delirium without prior chronic confusion, but that some experienced both. I also considered delirium to be a misunderstood mental illness which could be prevented and controlled given the correct interventions, but believed that often older people did not benefit from preventative care in fast paced hospital environments. I assumed that delirium was frequently misattributed to chronic confusion or aging in older people and I imaged that many health care staff found patients in delirium difficult. I wondered if some of this difficulty arose from odd behaviours during hyperactive delirium and the consequent erratic disruption of care routines. Later I wondered if it was possible that health care staff felt lost or inadequate in trying to provide information and advice to family members, as they themselves might not fully understand what was happening, be fearful or lack understanding of the nature of delirium. I felt family members were relied-upon to care for their loved one, a role I assumed not all family members wanted nor felt comfortable with during delirium. I wondered if some experiences during delirium would reverberate and retain their impact well after the event had passed.

It occurred to me that family members would encounter delirium either through visiting hospitalised older people, through visiting residential aged care settings or from providing care in the home. The idea of being with the older person during delirium was at the fore of my mind and I wondered what this was like for other family members; other daughters, sons, husbands and wives. I thought that delirium was confronting and that it would be distressing and frightening when the older person’s behaviours were aggressive, childlike or involved hallucinations and delusions. I wondered if family members felt trapped with the older person, perhaps under the watchful eye of health care staff or other family members, and in an environment cloaked by an air of illness, treatment, or possibly death. I questioned whether their delirium experience would stand out, be noticed and a worry, even if they were familiar with chronic confusion or caring in a context of unusual behaviours.
At the same time I thought that the attention of health care staff during an older person’s care would be focused on treating the older person’s illness and that the thoughts and needs of family members would be largely assumed, considered secondary or overlooked altogether. I thought health care staff may be offhand about encountering delirium, possibly a consequence of their frequent exposure to its unfamiliar and challenging presentations or possibly to their frequent encounters with older people who have dementia or assumptions about ageing.

Fellow nurses had shared their experiences with me and it seemed they often found caring for patients in hyperactive delirium frightening and difficult. I then wondered why it was okay to ask family to stay and provide care. I decided that it was important to hear the stories of family members; to hear from them what delirium was like and what was on their mind. Underlying this interest and curiosity were assumptions that family members would be accessible to me, willing and ready to openly discuss their experiences and able to explicitly express what this was like for them. I understood that asking family members to be involved in the study was asking a lot. I also considered family members to potentially be in a vulnerable state from either deterioration in their own health, concern for the health of the older person and their behaviours or the demands of being with them. I was aware that I would be asking that they recall and tell me about their experiences, a story potentially about a sensitive or emotionally charged topic and an experience which was possibility felt as frightening, difficult or painful. I wondered if some family members would also perceive an older person who hallucinates or hears voices, to be deviant, violent, or unstable and that they might need psychiatric care, restraint or locking away. To prevent being associated with what could be perceived as a stigmatising condition I thought it was possible that they might prefer to hide their experiences from others, including other family members, health care staff and me as a researcher. I was concerned that they may find involvement in the study distressing and that it could leave them feeling more vulnerable or upset and that they may distance themselves.

Underlying my thoughts was an assumption that the experiences of family members would be long and poignant enough to enable family members to recall their experience in depth. I also believed that family members would be willing to trust me enough to disclose their stories beyond a simple description of events. Possibly because of my own experiences of delirium, I assumed these experiences were meaningful but wondered whether I would be able to grasp and appreciate the perspective other family members described without shadowing this with my own perspective. I hoped that hearing other family member descriptions would challenge
the ways I already understood the experience of delirium. One of the challenges was the way scientific pre-understandings were developed, largely through considering the background of the study and reviewing the literature and, though I did not feel like an expert on delirium, these insights had the potential to hinder understanding delirium from the perspective of family members. These prior understandings are made transparent in Chapter 1: Study Introduction and Chapter 2: Literature Review, and were the subject of ongoing reflection during the study, particularly during later data analysis and interpretation.

Continued attention was given to uncovering, exploring and questioning my assumptions and pre-understandings, and the influence these were having on how the experiences of family members in the study were being collected and understood. I paid careful attention to the way I asked questions during each participant interview and during reflection afterwards I considered how I asked and encouraged each participant to describe their experience. During analysis and writing activities I used discussions with my supervisors and their questioning approach to bring forth assumptions and pre-understandings within interpretations or in ways I was changing the study to explore delirium experiences further. It was important to return to the phenomenon of interest, the way I was searching for lived experiences, and to the contexts for family members and the study. Also important was allowing time to contemplate the lived experience materials I had collected and the process of recurrent attention and questioning of parts and the whole of my experiential data so I could change or confirm my evolving interpretations (Munhall, 2007; van Manen, 1990). Critiquing my own thinking, writing, reflection and adopting an attitude that was open to different possibilities helped to bring to consciousness, explore and clarify assumptions and personal understandings as the study progressed. Practising in this reflexive mode was important to the way delirium as a lived experience for family members was investigated, and was important to the confirmability of the study.

**Investigating Experience as it is Lived**

Consistent with a phenomenological approach to research, I searched for and collected lived experience materials which would enable experiences of delirium to be explored, from the perspective of others, to disclose their meaning. An attentive openness to the varied appearances of delirium was called for, as was a mindset which valued the unique subjective perspective of each participant and connections between the participant, their experience and their life context (Munhall, 2007; van Manen, 1990). Different lived experience materials were collected to gain insight into the fundamental
and complex nature of older person delirium. However, as I wanted to privilege the experiences of family members themselves, I primarily collected their first hand experiential descriptions using interviews. Supplementing these descriptions were field notes and reflections from interviews, including observations of the context of each family member, enhancing my understanding of each participant and their situation (see Figure 1: Data Sources below). Moreover the field notes added to the credibility and transferability of the study by augmenting data sources that could be used later during reflection, analysis and interpretation of interview data.

Figure 1: Data Sources

In addition to interview data, field notes and reflections, I wanted to locate other varied appearances of older person delirium (see Figure 1: Data Sources above). Personal descriptions of my experience as a family member were recorded as narratives and considered with experiences of family members. Also collected were personal reflections documented throughout the study, particularly reflections from ongoing personal experiences and interactions with other people who experienced delirium, including incidental conversations with nurses and reflections after visiting participating hospital wards. I also collected poetry, novels, children’s books, music and images of delirium from popular literature and the internet. The etymological origins of delirium and expressions used by participants were explored, an exploration that helped to appreciate influences of language and differences in meaning. This included a connection to historical and differing contemporary meanings, understandings which have been shared in Chapter 1: Study Introduction.
Collecting Family Member Experiences

The following sections detail how descriptions of family member experiences during their older loved one’s delirium were collected. Included is a description of the family members of interest to the study, how family members were accessed and invited to participate, and the difficulties encountered. Also included is a description of the consent processes, the participant sample, and key ethical issues considered and encountered as the study unfolded.

Family Members of Interest

Throughout the study my interest was in accessing people who had had a particular experience, an interest suited to purposive sampling. During the initial participant recruitment period I was interested in locating and talking with family members who had visited their hospitalised older loved one (> or = 65 years of age) when they had delirium, as evidenced by either a medical diagnosis of delirium or a positive Confusion Assessment Method (CAM) assessment result. As an internationally recognised instrument to guide delirium diagnosis (Adamis, Sharma, Whelan, & MacDonald, 2010; Thomas et al., 2012), the CAM was considered appropriate for use as part of the selection criteria. In a seminal paper by Inouye et al. (1990), the CAM is reported to have high sensitivity (94-100%) and specificity (89-95%) for delirium identification. Importantly Thomas et al (2012) has reported the CAM as diagnostic for delirium compared against both the International Statistical Classification of Diseases and Related Health Problems (10th Revision) (National Centre for Classification in Health, 2006) and DSM-IV diagnostic definitions (American Psychiatric Association, 2000). In addition, the CAM is used widely in both clinical and research settings (Dahlke & Phinney, 2008; Inouye et al., 2001), including the hospital involved in the study.

Initially I was interested in listening to family member descriptions if their loved one did not have a history of dementia, Alzheimer’s disease, acute brain injury, terminal illness, cerebral infarction or psychiatric diagnoses. At the time I thought that I would be able to access sufficient family members for the study and that excluding older people with these diagnoses would locate family members in a similar context and enable a clearer view of their experiences during delirium. As I was concerned about the potential for family member vulnerability, the family members I wanted to access were those who were, at the time of recruitment, visiting an acute hospital ward other than the emergency department, intensive care, coronary care, burns unit or high dependency unit. Three hospital wards (general medical and older person care, orthopaedics and
emergency transition care of the older person) were therefore initially adopted as settings through which family members were sought and invited to be participants.

To enable me to listen to their descriptions, all family members needed to be able to communicate in English and willing to be interviewed on at least one occasion. They also needed to be able to give voluntary and informed consent. Due to financial and time constraints, participants needed to be willing to be interviewed at a location within two hours’ drive of the study location. I was aware of different types of family composition and thought that it was important to be open to participation by a broad range of interested family members. With this in mind I used a broad definition of family membership (see Chapter 1: Study Introduction), and neither deliberately sought nor excluded family members aged between 13 and 18 years of age and those from culturally, ethnically or socio-economically diverse backgrounds. Moreover family members with prior experience of delirium were not excluded. Whilst initially I wanted to access family members who were in the midst of experiencing their older loved one during delirium my focus later broadened to search for other family member experiences during delirium. Using a purposive approach throughout the study added to the study’s credibility and, detailing how it was achieved, enhanced study transferability.

**Accessing and Inviting Family Members into the Study**

After gaining the relevant ethics committee and hospital administrator approval, as described later in this chapter, I commenced the study by attempting to access family members through three wards of one regional public referral hospital located in New South Wales, Australia. As I was not an employee of the participating hospital I was concerned about the privacy of the older people in their care and vulnerability of family members at the time they were approached about the study. I therefore asked ward nursing staff with clinical expertise in delirium identification, and a clinical relationship with the older person and their family members, to act as recruitment intermediaries. For this study, Nursing Unit Managers (NUMs) from participating wards and the Clinical Nurse Consultant (CNC) for Dementia and Delirium Acute Care filled this role and approached family members. After the study commenced, and with ethics committee approval, the Clinical Nurse Consultant for Trauma and Orthopaedics also acted as an intermediary. To prepare the intermediaries for their role I met with them individually and as a group. In these meetings we discussed the aim of the study, inquiry activities, ethical issues in approaching potential participants and study inclusion criteria. Each NUM and CNC was provided with a recruitment information pack (see Appendix B)
which contained recruitment information, study inclusion criteria checklist, CAM form, participant study information statement and invitations, participant consent forms, and the ward poster used to advertise the study. Each NUM and CNC was also given a supply of family member study information packs which contained a participant study information statement and invitation, participant consent form and addressed reply paid envelope (see Appendix B).

The intermediaries were to identify older people with delirium and approach family members about the study during their visits to the older person. In addition, family members could approach the NUM about study involvement after reading study information posters displayed in each participating ward (see Appendix B). The intermediaries were asked to inform family members about the study, inquire about their interest in being involved and, when interested, provide a family member study information pack. Interested family members were requested to return a completed consent form to the researcher using the supplied addressed reply paid envelope, and to contact the researcher if further information was needed. Family members were advised that the researcher would make contact only when a consent form was returned.

Throughout the recruitment period regular contact was maintained with the intermediaries to provide support, to clarify recruitment processes and advise on changes to the study design or ethics approvals. With delirium as a shared interest, questions were invited about the study and the intermediaries spontaneously shared their incidental nursing experiences with delirium. As the study progressed it emerged that these were often experiences of delirium superimposed on dementia which, in hindsight, was not surprising as dementia is recognised as a major predisposing factor for delirium in older people (see Chapter 1: Study Introduction). Despite delirium presenting in different ways, including hypoactive and mixed sub-types (see Chapter 1: Study Introduction), most of the older patients intermediaries recognised as having delirium were described as having hyperactive behaviours. This reflected the nurse experiences described in the literature (see Chapter 2: Literature Review), and possibly the more obvious nature of hyperactive delirium behaviours and the more invisible and less disruptive nature of hypoactive delirium.

Visits to the wards and discussions with nursing staff provided an opportunity to question assumptions, observe the context of each ward, a context similar to that where many family members in the study experienced being with their loved one during delirium. I realised that I would gain insight into each family member’s situated context
from experiential descriptions, however visiting the wards offered an opportunity to gain a broader sense of this context as a place and of hospitals as spaces where family members would be with their older loved one. At times during these visits I felt like an outsider, someone less familiar with hospital and ward activities than my nursing background might have predicted. However, this helped me to gain a sense of the ward environment as a visitor rather than a nurse responsible for patient care, and also meant that I was neither connected to the care of patients nor identifiable to family members on the ward at the time. Visiting the wards allowed sustained engagement with a context similar to where many family members experienced delirium in the study.

**Difficulties in Accessing Family Members**

Despite my initial optimism and faith in anecdotal information about the number of older patients with delirium, difficulties in accessing family members were encountered during the recruitment period. After twelve weeks of recruitment only two participant information packs had been distributed and only one family member had entered the study. I thought, in discussion with the intermediaries, that the admission of older patients to each ward was negatively affected by bed shortages and a need for emergency department admissions to be transferred to wards which were not participating in the study. These older patients were often referred to as “outliers” by ward staff. To improve access to family members the recruitment location was therefore initially varied to include older people who were admitted to the treating medical and surgical teams of the participating wards rather than the ward alone. Despite this variation access to family members did not improve. This, along with descriptions from intermediaries of their experiences of delirium on their ward, prompted re-consideration of the inclusion criteria and recruitment settings. Anecdotal data suggested that fewer older people meeting inclusion criteria were being admitted than anticipated, and that there was an unexpected increase in older patients diagnosed with delirium superimposed on dementia, so excluding these family members. Initially I was concerned that family members would not differentiate between acute and chronic confusion, however discussions with the intermediaries suggested that this was not the case. They viewed family members as more aware of acute changes in the older person than treating health care staff. I considered changing the inclusion criteria of older people to include delirium superimposed on dementia to be an improvement to the relevance of the study and its findings to health care staff. Although delirium and dementia are both characterised by what nursing staff called “confusion”, this change in focus better reflected the context in which delirium is experienced by family members of older people. The inclusion criterion for older loved
ones was subsequently varied and approved by the relevant ethics committees to include older people with pre-existing dementia or Alzheimer’s disease.

Despite the inclusion of dementia and Alzheimer’s disease in the participant inclusion criteria, after seven months I continued to have only one participant join the study. I therefore sought additional avenues for accessing family members with experience of delirium. Help was requested from the participating hospital’s Psychiatric Liaison Team. In the participating hospital delirium in older people was at times considered a psychiatric or mental health problem and staff involved with the care of older people requested assessment and management advice from members of the Psychiatric Liaison Team. In the previous twelve month period this team identified delirium in 127 patients at the participating hospital, supporting this avenue as a viable recruitment strategy. To identify older patients diagnosed with delirium by the Psychiatric Liaison Team permission was provided for the CNC in Dementia and Delirium Acute Care to access routine weekly patient diagnosis reports through an approved variation to the ethics approval for the study. While it was planned that the CNC would identify older people with delirium, confirm they met the study’s inclusion criteria and introduce the study to visiting family members, no further study information packs were distributed using this approach. Going back and forth and looking for different ways to find family members with experience of delirium had become a contradictory experience; on the one hand there were older people with delirium and yet on the other, finding family members who could share their experiences was difficult.

Difficulties in accessing and inviting family members into the study continued and further revision to the study was required. After 13 months of recruitment and despite prior changes to the study’s design, only seven information packs had been distributed to family members by intermediaries and only one family member had joined the study. The situation called for the phenomenon of interest, research question, the study context and my assumptions to be reconsidered. I asked what was going on in the context, for family members and for older people during delirium, and asked why it was so hard to access the experiences of family members? Several possibilities were considered as contributors to this unforeseen situation, including the prevalence of diagnosed delirium in older people admitted to the hospital, difficulties with the diagnosis of delirium including misdiagnosis as dementia, multiple changes to intermediary personnel related to hospital and leave arrangements, difficulties in matching intermediary availability with visiting times of family members, intermediary workloads and clinical priorities, the focus on identifying family members secondary to older people with delirium and possible gate keeping behaviours by intermediary staff.
As I asked what was going on in the study the very basis for research focused on hospitalised older people was challenged. I reconsidered what the phenomenological perspective called for and reflected on the situatedness of each family member, how this might influence their experiences and what was meant by understanding the experience of family members. This questioning process prompted me to reframe the research question and study aim, a change that reflected an approach which would be less contextually rigid and more open to the diversity of family member experiences. What I became interested in was seeking family members themselves; those with experience of being with their older loved one during delirium rather than older people receiving acute hospital care and then their family members. Essentially, I felt I had the recruitment focus back-to-front. This change was more consistent with the study’s methodology, one which encourages exploration of all appearances of the phenomenon, is interested in the context of experiences and focuses on the person who has had the experience (van Manen, 1990). I had also thought that I needed to speak with family members during their experience, rather than understanding what Morse (2000c) argues is the legitimacy of interviewing afterwards, particularly given known levels of distress felt by family members during delirium (O’Malley et al., 2008), and the possibility of the older person’s death near or at the time of family member experiences (DeCrane, Culp, & Wakefield, 2011; McCusker et al., 2002). As suggested by Morse (2000c) the validity of asking family members to describe their experience is not concerned with actual events as viewed from the outside (Sartre, 1943/2003), but is concerned with human experiences and responses, a description of which is aided by a resurgence of memories and emotions elicited by asking about their experience after the event. In addition, as noted in Chapter 1: Study Introduction, delirium occurs in older people in a range of contexts; in community dwelling older people, those with pre-existing dementia, older people living in residential aged care services and those in acute care hospitals (Bucht et al., 1999; Cacchione, Culp, Laing, & Tripp-Reimer, 2003; Folstein, Bassett, Romanoski, & Nestadt, 1991). Refocusing recruitment processes on family members themselves enabled direct access to the people of interest to the study and those who may be interested in participating. It was also thought that this approach would provide family members with an opportunity to consider participation at a time when they may be more ready to talk about their experiences and with someone who is perceived to have less connection to the care or care setting of their loved one. Morse (2000b) refers to the dilemmas and decisions I faced as “following your nose” (p. 579). In Morse’s (2000b) view, these decisions acknowledge that the design is not working or keeping pace with changes in potential participants or the natural setting. Rather than
being a problem, the difficulties I faced reflected the way the study needed to emerge to better understand family member experiences.

My interest consequently shifted away from the acute hospital context to family members with experience of being with their older loved one during delirium more generally. Taking this new direction called for changed ways of accessing and inviting family members into the study, in particular a strategy that would provide access to family members directly. Several options were considered including newspaper advertisements and visiting carer support groups however, with ethics variation approval (see Appendix F), family members were accessed via the Hunter Medical Research Institute (HMRI) Research Register.

The HMRI was established in 1998 as an Australian translational medical research institute (HMRI, 2013), drawing together biomedical, clinical and public health researchers from Hunter New England Local Health District, the University of Newcastle and Calvary Mater Newcastle (HMRI, 2012). Its purpose includes facilitating collaborations between researchers and translating research outcomes which are closely aligned to community health needs (HMRI, 2013). Research foci include brain and mental health, cancer, cardiovascular health, information based medicine, pregnancy and reproduction, public health, viruses, infections/immunity and vaccines and asthma (HMRI, 2013). Part of HMRI’s activities has been the creation of a Research Register to help health researchers to access the participants they need for research (HMRI, 2013). The register was established in 2005 and provides a database of healthy people located in the study area who were interested in participating in health research (n=1,614, aged 18-90 years irrespective of medical history) (HMRI, 2011, 2013). Initially researchers used the register to access healthy control participants for quantitative research, however over time qualitative researchers have also used this resource.

Utilising a register to access family members was a broad recruitment strategy which relied on finding family members with the specific required experience from within a pool of community members, albeit people with an interest in participating in research. To maintain confidentiality register members identified to receive a study information pack were selected by a member of HMRI’s staff with responsibility for the register. As register member details were limited, members were selected to receive study information based on their age, absence of known cognitive impairment and English language skill. The initial distribution of study invitations occurred through HMRI in August 2011 by mail (n=100). A second occurred in September 2011 (n=100) as no
family members had expressed interest in joining study after the initial mail-out. In total 200 register members received a HMRI Research Register letter of invitation for the study, study information letter and invitation, study consent form (see Appendix C) and an addressed reply paid envelope. Following the mail-outs completed consent forms were received over three months, from September to November 2011 (n= 24, initial mail-out n=14, second mail-out n=10). As it was possible that further family members would respond and as I continued to assess interview data depth and breadth from participating family members, the recruitment period remained open until January 2012. However, no further responses were received.

Although researchers using quantitative methodologies often access registers of people interested in participating in research, utilising a register for this study did not seem to be a natural fit and required consideration of the impact of this approach on the nature of potential participants. Many of the register members included in this study acknowledged involvement in multiple research projects, enjoying involvement in some but not others. Most commented that they had not been involved in qualitative research or in-depth interviews before, and expressed an interest in this different approach. Clearly evident was a high level of motivation, familiarity with research requirements and processes, and sound knowledge about research participation.

Broadening the approach to accessing family members for the study called for further variation in how study inclusion criteria for the older person and their family member would be addressed. Accessing family members away from a clinical context meant that I would no longer be able to confirm the presence of delirium through the older person’s medical record nor clinician assessment. Rather, I drew on the judgement of family members in identifying when their loved one had experienced an episode of acute confusion or delirium, whether experienced alone or superimposed on dementia. Although it is argued in the literature that delirium is a clinical diagnosis made at the bedside (Fong et al., 2009; Page & Ely, 2011), the revised approach was consistent with the views of Fick, Agostini & Inouye (2002) and Fick and Foreman (2000) who acknowledge that family members have insight into the older person’s usual behaviours and when this is different, a knowledge that is thought to be more sensitive than nurse or medical officer assessment (Armstrong et al., 1997; Fick & Foreman, 2000; Fick, Hodo, Lawrence, & Inouye, 2007; Inouye et al., 2001; Laurila, Pitkala, Strandberg, & Tilvis, 2004; Voyer, Richard, Doucet, Danjou, & Pierre-Hughes, 2008). Fick and Foreman (2000) report that interviewed family members (n=13) recognised an abrupt change in mental state in the older person even though this was superimposed on pre-existing dementia. In addition, Trzepacz (1998) argues that delirium symptoms
occurring concurrently with dementia are very similar to those of delirium alone, with delirium symptoms dominating symptoms of dementia. As reported in Voyer et al.’s (2011) study, the CAM can also be successfully used to identify delirium in older people with dementia. In essence the new recruitment approach was similar to clinician reliance on health history from family members to clarify the older person’s symptoms, the timeline and relationship with usual cognitive function.

I therefore embraced each family member’s expertise and discussed the changes they noticed during initial telephone contact and after receipt of a signed consent form. One of the aims of this conversation was to assess the changes recognised by family members against CAM criteria. An abrupt change in mental state and fluctuating course combined with a trigger change in an underlying medical condition or development of a new acute condition (e.g. urinary tract infection) were identified to maintain consistency with DSM-5 definition of delirium (American Psychiatric Association, 2013), and in recognition of Thomas et al.’s (2012) findings that acute onset and fluctuating course are the most important changes for identification of delirium (Thomas et al., 2012). An interview was planned with the family member when the experience described was consistent with these revised selection criteria. To further corroborate inclusion in the study each initial interview was reviewed for concordance with the characteristics of delirium, and family members subsequently excluded from the study if concordance was doubtful.

When sufficient participants were recruited to the study, intermediary and Research Register involvement in recruitment ended (September 2011 to January 2012). No further invitations to participate were distributed after this time and no further expression of interest were received from either recruitment process.

**Participant Sample**

After broadening the recruitment approach and a total recruitment period of 18 months (1st August 2010 – 31st January 2012), 207 study information packs were distributed (Research Register members n=200; family visitors to participating wards n=7; hospital Psychiatric Liaison Team referrals n=0). Consequently 25 completed consent forms were returned, almost all arising from Research Register members (n=24). Subsequently 11 family members drawn from the Research Register were excluded (8 family members as a result of initial phone contact and 3 after their first interview). The reasons for exclusion were non-family member status, experiences of dementia alone or experiences of an acute episode of an existing psychiatric condition. One completed consent form was returned by a family member visiting their loved one on a
participating ward. Thus, 14 family members participated in the study, all of whom were women. A profile of the participants as a group and biographies for each woman are presented in Chapter 5: Findings Prologue.

The reasons for family members not agreeing to participate in the study after receiving a study information pack are unknown. For those receiving invitations via the HMRI Research Register it is likely that register members did not assess themselves as meeting study inclusion criteria, were not interested in the study focus or preferred not to be involved on this occasion. Given previously described distress related to delirium experiences (see Chapter 2: Literature Review) it is also possible that some family members might not have wanted to recall and describe their experiences, or feared talking about changes which might be associated with mental illness.

The final number of participants included in the study was guided by the data collected and what was needed to answer the research question rather than aiming for a representative, reliable and reproducible sample. Of particular concern in making decisions about participant numbers were how richly participants were able to describe their experiences, the variations in their descriptions, disclosure of aspects of themselves, and the amount of data collected from each woman, all qualities needed to enable later analysis and to achieve credibility and transferability (Leininger, 1994; Lincoln & Guba, 1985; Morse, 1995, 2000a). The interview data from the 14 women was judged to be adequate to provide a group of comprehensive individual and detailed descriptions which lent themselves to in-depth analysis. Though the participants were all women, I considered a group of women to be suitable for exploring the meaning sought by the research question. It was not surprising that all the participants were women, given the higher proportion of female to male carers for older people and people with a disability in the Australian community (Australian Institute of Health and Welfare., 2004), and the study’s focus on family members. It was important, however to remain mindful that the experiences of men were not voiced, perhaps experiences that could reveal further or different understandings.

The women volunteered to be part of the study for their own reasons and these motives were not directly explored. It is possible that they too were curious about delirium and wanted to express their experience to someone who they perceived to be interested. Or perhaps they saw it as a chance to debrief with someone who might understand, or to ask about their experience. Possibly there was an emotional investment and they hoped that their experience could be shared and would help other family members in the future. No matter their reasons each woman generously gave
her time and shared her unique experience, experiences which touched me as a daughter, wife, nurse and researcher. Many of the experiences described were challenging to listen to. At times this was for the women’s strength and resilience during troubling or difficult times and others for their experiences of insensitive health care staff, systems and processes. The clarity of their recall was often surprising, particularly when some experiences had occurred some time ago (see Chapter 5: Findings Prologue). Perhaps this illustrates the poignancy of this experience and the impact on the women’s lives, an impact that should concern health care staff.

**Family Member Interviews**

As noted earlier, I was curious about what it was like for family members to experience being with their older loved one during delirium. I wanted to listen to family member accounts; to be drawn into their existential world, hear what their experiences were like and listen to what was on their mind. To achieve this, I collected in-depth descriptions of the women’s experiences through semi-structured interviews. The interview material was initially in the form of digital voice recordings and later typed transcripts. Consistent with a phenomenological research approach, these materials were based on turning to those with lived experiences important to the research question, and the view that the women’s reality was the perspective important to the study (Kvale & Brinkmann, 2009; van Manen, 1990).

To help me to enter into the women’s world and their experience I asked the women to talk to me on one occasion and then invited participation in follow-up interviews. This provided the women with an opportunity to describe their experience and to later add depth to their description without possibly feeling committed or daunted by a set of interviews. Conversations were collected over a period of approximately 19 months, from late August 2010 to mid-March 2012. The location of the interviews varied depending on each woman’s preference. One woman preferred to be interviewed at the hospital, but away from her husband’s ward. Others preferred to be interviewed in their own homes, at the university, or in a public space. These locations meant that at times the interviews were interrupted by noise, unanticipated activities or the unexpected arrival of other people. On these occasions we would pause and wait until privacy and quiet were available again. While I offered no explanation for my presence, the women often explained to interlopers that they were talking to a researcher. Surprisingly the interruptions did not appear to interfere with the women’s descriptions as each picked up the thread of their conversation quickly and continued on without prompting or hesitation. Interviews held in an office at the university initially created
some difficulty for me in focusing on the task at hand however, despite my own initial difficulties, the women seemed comfortable with this context and openly told their experience.

My initial intention had been to interview each woman on her own and in private however, for three women in the study, this was not what they had in mind. At one interview I encountered two sisters, both wanting to be interviewed together. This situation was unexpected and caused me to pause and consider the ethical implications of this unplanned situation. Grateful for the offer of tea I had time to think and was able to talk to each woman alone and confirm that they wanted to be interviewed together and were aware that this might call for disclosure of information that they were not comfortable expressing in front of one another. As joint carers for their mother it was important that they told me about their experiences together. On another occasion I arrived to interview a woman in her home, only to find her husband was also present. During our initial conversations it became clear that as her husband had dementia and she was a full time carer, she was not able to leave him. After confirming consent for her husband’s presence we completed the interview, being mindful that at times we were talking about her husband in his presence. Though I thought this would be difficult for the woman and her husband, they seemed un-phased and participated in the conversation as they saw fit. Whilst neither of these situations was ideal, they represent the dynamic nature of qualitative research and the challenges, ethical and otherwise, that can be unforeseen.

Each interview was guided by a broad interview schedule approved by the Human Ethics Committee (see Appendix D). A conversational style was used to complement the open interview structure and open style of questions. At the start of each interview I aimed to help each woman to feel comfortable and then, as we progressed, adjusted our conversation to their needs and direction. I introduced myself, broadly discussed the study and answered questions. The interview process was described, including estimated duration, freedom to refuse to answer any question or end the interview at any time. I asked permission to digitally record each interview, showed each participant the digital recorder and how it would be used. Participants were asked if they were willing to review their interview transcripts and reassured that changes required no explanation or justification. Anonymity was discussed including data confidentiality arrangements, safeguards for the planned use of an independent transcriber, and use of pseudonyms in transcribed interviews and future publications. Permission was sought to use first names and to take brief field notes.
At the start of each conversation broad open questions were used to orient our attention to each woman’s experience. This style of question appeared to encourage each woman to start to talk, to disclose aspects of their experience that they considered important and to respond in a flowing narrative that helped to prevent descriptive narrowing. The direction for our conversation was taken from the evolving path the women provided in their account and, in later interviews, I invited the women to extend their account around these directions and the insights they provided. Using short encouraging statements, timely open and clarifying questions during the interview appeared to help the women to know that I was listening and encouraged them to continue to respond in-depth. With very little input from me during our conversations, the integrity of each woman’s description was enhanced. Within each woman’s tolerance, I explored the nature of their experience of delirium and went as deep as they could tolerate or wanted to share. Although all participant accounts were considered valuable to my study, some accounts were more detailed than others and revealed more of each woman’s place and experiences in the world. I was also aware that aspects of each experience could be lost during later transcription so I aimed to observe non-verbal communication and verbal emphasis. As each woman responded I took very brief notes to act as aids for additional or clarifying interview questions and to aid reflection and analysis after the interview.

As I followed each woman’s account I remained open to what they wanted to tell me about their experience. At times this meant I needed to acknowledge my concern that the description was wandering away from what I perceived my research question to be about. I mentally reaffirmed the need to trust each woman’s lead and that later these wanderings would make sense within the context of their whole experience and be significant to understanding concealed meanings for each person. I attempted to hold my pre-conceptions and assumptions at bay and to listen openly and attentively to the experience from each woman’s point of view rather than my own, all the time considering the influence of researcher distortion on the credibility of the study. While this position was helped by my curiosity about the experiences of family members, at times it was difficult. Central to many of women’s stories was the health of their loved one, their progress or care. They sought reassurance that their loved one’s care was appropriate, that their health was improving, or that delirium would be cured. These inquiries asked for a nursing rather than researcher response. Similarly information was at times sought about delirium as a condition in older people.

Each interview came to a close when our conversation naturally came to an end. The length of each interview therefore varied depending on each woman’s interest, capacity
to talk, commitments or priorities for the day, and at times their emotional response to sharing their experience with a stranger. On average interviews lasted for 40 minutes, but ranged in length from 24 to 85 minutes. I was able to have more than one interview with all but four participants (one interview n=4; two interviews n=9; three interviews n=1), culminating in 23 recorded interviews or 885 hours of recorded interview time. The reasons for not progressing to a second interview were the extensive depth of the initial description, the woman’s health status and changes to family circumstances. Opportunities to have more than one interview with the women built trust and allowed me to ask for clarification and explore aspects of these women’s experience in greater depth. All the women in the study were able to recall and describe their experiences of delirium in depth.

In the interviews the women used their own words to voice their perspective and provided detailed nuanced descriptions of their particular experiences. The women’s interview conversations about their daily life provided privileged access to personal experiences of their lived world and provided recorded personal, contextual and unexplained representations of each family member’s conscious subjective point of view. The women also spoke about other people or, as Morse (2001) describes shadowed data, revealing subtle nuances to meanings in the women’s perceptions and experiences. In addition, field notes were recorded during and after each interview to capture observations, ideas and incidental insights related to each woman, their experience and their context.

The length of my interaction with each woman varied, however most continued over several months, providing the period of sustained engagement needed for study credibility. For one woman our interactions were ended when her loved one was discharged from hospital and she took on responsibility for his care at home. All others ended when the women felt they had no more to tell. Interviews with many of the women where emotionally charged; many of the women cried. Although distress was anticipated the intensity of the women’s sadness spoke to me as a nurse and daughter, at times making it difficult for me to respond as a researcher. How I managed these situations is described later in this chapter.

Reflections on each conversation and a participant profile were crafted a short time after each interview. These profiles provided a life context and background within which each woman was immersed during her experience and formed part of the material for later data interpretation. In addition, these detailed individual profiles assist readers of
the study to judge the study transferability and trustworthiness. Each woman’s profile is presented in Chapter 5: Findings Prologue.

Although I thanked each woman for her contribution to my research and for sharing her experiences with me I found breaking contact with the women difficult, possibly as they had wanted to talk about their experiences and had given so much of themselves for my research. Experiencing the women’s generosity, trust and interest in what I was doing was humbling; I felt privileged to have shared time with each of them.

The lengthy period of time over which the interviews were completed allowed me to organise and begin to analyse the data before all data was collected, a process described later in this chapter. I therefore wanted to access validated interview transcriptions as close to the time of recording as possible. A paid transcriber was engaged for this purpose. I realised that releasing data to a third person could pose risks to participant privacy and confidentiality so I discussed the confidential nature of the data with the transcriber and required a signed confidentiality and data security/storage undertaking (see Appendix E). Each interview was transcribed in full and using a pseudonym. I also recorded the duration, date and location of each interview. I felt that it was important for the women to have an opportunity to revisit their conversations soon after their interview so I invited them to read and confirm or make changes to their transcripts without explanation. After checking the initial transcriptions for accuracy with the digital recording I returned the transcripts to the women. Returning the transcripts to participants maintained the women’s authority and verified their standpoint within the data, adding to other strategies that enhance study credibility. Two women made minor changes, primarily grammatical adjustments or clarification of places and people. When transcript changes were made the transcriptions were considered ready for analysis.

**Ethical Considerations**

Inherent in all human research is the need to consider and protect the welfare and rights of participants. To uphold procedural ethical and legal responsibilities I sought approval to proceed with the study from the relevant area health service human research ethics committee and subsequently registered this approval with the university human research ethics committee (see Appendix F). Three variations to the original application were subsequently submitted and approved, each aimed at

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3 The Human Research Ethics Committee for the Area Health Service responsible for the hospital participating in the study.
improving access to study participants (see Appendix F). The original study and changes to its design and methods were implemented after approval and registration with the relevant ethics committees. Though this evidences compliance with ethics approval processes I was mindful that conducting research always requires an appreciation of the context of the research, ongoing deliberation on the application of ethical values and principles, and the exercise of judgement. Therefore the values and principles of ethical conduct described in the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, Australian Research Council, & Australian Vice-Chancellors’ Committee, 2007 - updated February 2013) formed part of my researcher attitude. This included consideration of the merit and integrity of my research, justice, beneficence, and respect throughout the study. As a consequence of sustaining this attitude several ethical issues were identified and addressed during the design and evolution of the study. These issues are now described.

**Beneficence**

In this study the principle of beneficence was important in balancing the need and desire for a better understanding of delirium experiences with an appreciation of the risk of harm or discomfort for the women. This was of particular importance as though the research was considered low risk according to the National Statement on Ethical Conduct in Human Research (NHMRC & Australian Vice-Chancellor's Committee, 2007 - updated February 2013) there was little direct benefit from study involvement. Important considerations were the potential vulnerability of participants at the time of interview, the impact of recalling and discussing their experiences, experiences which were potentially about a sensitive topic. Based on research into delirium experiences I had come to understand that participation in delirium research could be challenging or distressing, particularly for family members (see Chapter 2: Literature Review). They may feel vulnerable for many reasons, including their visitor status when with their loved one, concerns for the health of their loved one, the nature of their condition, deterioration in their own health status, their age, or through the process of describing their experiences. Family members may be distressed about their older loved one having an acute illness, being admitted to hospital, and suddenly behaving in ways which are foreign to them. As delirium in older people is also associated with severe illness and a high mortality (Eeles et al., 2010; McCusker et al., 2002) it was also possible that participants might fear or have recently experienced their loved one's death. In addition to feeling vulnerable there was a possibility that the women would consider delirium a sensitive or even taboo topic. When delirium is present, older
people can behave in ways that are uncharacteristic, socially unacceptable and which suggest a change in mental health. Sensitive research topics are thought to create a level of risk or threat for participants (Kvale, 1996; Lee, 1993), so adding to potential participant distress, burden and vulnerability. These considerations could cause fear, distress and discomfort and needed to be addressed.

Based on these risks and concerns I briefed recruitment intermediaries before recruitment commenced and discussed concerns about participant sensitivity and vulnerability. The importance of being mindful of family member and older person apprehensions about delirium, knowledge of the older person’s condition and family member distress levels when approaching them about the study was confirmed. Due to the behavioural changes known to characterise delirium and the documented experience of family member distress (Breitbart et al., 2002) I limited the age for possible young family member participation to 13 years and older. Participants who were invited into the study through the Research Register were able to decide, away from the researcher and over time, if they felt able to participate. It was also important to confirm family member understanding of the study, its focus on delirium and what would be discussed before progressing to the first interview. Family members were contacted by phone for an informal conversation about the study when their completed consent form was returned by post, allowing the potential for distress to be considered for each participant at this time. When family members indicated they were aware of the study’s focus, that they remained interested in continuing, and seemed able to discuss their experiences without immediate distress, arrangements were made for the first interview. Each interview was then conducted at a venue the women preferred, in a manner which encouraged the development of trust in the researcher, and paid attention to the context and reactions of each woman. Each time we met I checked that they wanted to continue and were able. The intent of each conversation was to facilitate the telling of their story in their own time and without judgement. Rather than avoiding the women’s emotions during their interview I was responsive and supportive. When the women cried, became sad, restless or uncomfortable the digital recorder was paused and a period of quiet and gentle verbal reassurance was provided. I asked if they wanted to continue and offered to end the interview without further explanation if they preferred. Interviews progressed only when each woman was ready and able. Time was spent after each interview to debrief and prepare to leave the interview. This included suggestions for self-care and accessing their family members/friends, general practitioner or counsellor, as appropriate, for support. The use of counselling services was encouraged where a need was identified. Some women commented that though it
was upsetting to talk about their experience they liked sharing what had happened. Where participants expressed a high level of sadness or distress I called them after their interview to check on their welfare and to ensure that they continued to have support available to them. For one family member I offered reassurance and encouraged withdrawal from the study. This participant chose to continue and completed a second interview.

Respect

Another important consideration was the principle of respect, particularly with regard to consent, confidentiality and protecting participant and loved one’s privacy. It was possible that the woman asked to participate in the study through a hospital ward would feel obliged to participate or may feel their loved one’s care would be adversely affected if they declined or withdrew. This signalled the possibility for passive coercion and a need to verbally reassure the women that participation in the study was voluntary and, as appropriate, unconnected to their loved one’s care. This was discussed and agreed with recruitment intermediaries and was revisited during interviews. In addition, interviews were not held on the ward, so separating my role as a researcher from the nurses on the ward and care environment.

Privacy

Throughout the study it was important to safeguard the privacy of the older person and women in the study. Particular privacy concerns were raised when family members experienced delirium while visiting their hospitalised loved one, a situation that linked the older person and their details to family member participants. To safeguard the older person’s privacy family members were provided with information about the study through nursing staff intermediaries, so distancing the researcher. In approaching and/or discussing the study with family members, the intermediaries did not record any of the older person’s details nor provide the researcher with details identifying the older person or family member. During interviews participants were requested not to fully identify their loved one and references to the older person in interview transcripts were de-identified. Interviews were also held away from the older person’s hospital ward and ward visits occurred before visiting times, preventing the researcher from opportunistically identifying the older person from the family member’s presence on the ward. As the study progressed a woman joined the study and included her husband in the interview. When this unanticipated situation arose privacy and consent were
discussed and consent obtained from the woman as her husband suffered from dementia. Her husband’s identity was treated as confidential.

To protect the privacy of family members the researcher did not have access to family member names nor contact details until a completed consent form was returned. No access was possible to the names and contact details of Research Register members and, as previously described, all mail-outs were conducted via the HMRI Research Register office. Once each woman consented to involvement in the study interviews occurred at a time and in a place which did not identify the family member as a participant of the study (e.g. not on the older person’s ward or at the Research Register office). To further protect participant identity all contact between the researcher and the women was direct rather than through the recruitment location. Participant details, including completed consent forms and hardcopies of written correspondence with identifying participant details, were kept in a secure location and as per the ethics approval.

Collecting Other Lived Experience Sources

To this point the discussion has concentrated on how the women’s experiences were collected as the primary source of lived experience data. However, consistent with a phenomenological approach to research, I was also interested in collecting other appearances of delirium, so developing a collection of lived experience material that could be reflected upon during analysis and interpretation of the women’s experiences. When employing phenomenology to inquire into the nature of lived experience van Manen (1990) encourages the researcher to turn to and consider a broad range of lived experience materials. He argues that when these materials are explored, the researcher’s lens of understanding is widened, so helping the researcher to come to the meaning of other people’s experiences. Furthermore van Manen (1990) suggests that each source has a place within the study when it contributes to understanding the experience of interest. Taking Pagett’s (2008) view that confidence in the data and its interpretation is enhanced when multiple data sources are used, the bringing together of varied sources also created a comprehensive picture of delirium and assisted in building study credibility.

Whilst collecting lived experience descriptions from the women and coming to understand their life context, I explored the idiomatic phrases and metaphors they used and collected other sources of lived experience material such as descriptions of my experiences as a family member and incidental encounters with delirium. I searched
academic and popular literature/music for and pondered lived experience accounts and images of people during delirium and contemplated what they depicted and meant (see Figure 1: Data Sources on p.138). The etymological and historical origins of the word delirium were also explored, putting me in touch with the living origins of delirium and possible lost meanings (van Manen, 1984, 1990) (see Chapter 1: Study Introduction). Tracing meanings for the word delirium connected me historically to meanings over time and helped me to appreciate the influence of language and differences in meaning. When these additional sources were brought into consideration it was important to contemplate what it was that made the women’s experiences the same or different from other human encounters during delirium and other phenomenon. Also important was allowing these sources to challenge interpretations I was making and to suggest meanings that I had not contemplated.

In the following sections I describe how these sources were collected and used to add depth and breadth to the study, to aid reflection, and to interpret the women’s experiences. The section on metaphors and idioms is drawn from the women’s descriptions and adds directly to the biographies shared in Chapter 6: Study Findings, further contextualising the women’s experiences and disclosing their world.

**Metaphors and Idiomatic Phrases**

The women in the study used expressive phrases to describe their experiences. At times these were metaphors or idiomatic phrases, emotive but safe language that seemed to help the women put to voice their experience and connect me to their world. Consistent with the phenomenological view that language is an expression of conscious intentionality in relation to the world (Stewart & Mickunas, 1974), and Merleau-Ponty’s (1945/2002) notion of language as a cultural object (see Chapter 3: Guiding Approach), the women’s expressions were considered to be rich with meaning and helpful in disclosing the nature of their experiences. I was hence attentive to each woman’s expressions, reflecting upon what they said with their interview transcript to provide further insight into their experience.

To help me see from the women’s perspective and to grasp the meanings of the women’s expressions, Wordles™ 4 were also created using their expressions. The Wordle™ titled Women’s Expressions (see Figure 2 on p.159) is one example of this approach, bringing together the phases, idioms and metaphors the women used to

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4 Wordle™ is a online tool that arranges words and phrases using different colours and formats (permission to copy and communicate this work has been granted by Feinberg (2013).
express the loss of their loved one and the place to which their loved one went during their experiences. Arranged together these words were viewed as an expression of the women’s experiences, an expression which evoked a sense of each woman’s experience and that of all the women. They challenged my prior understandings and drew me into the women’s perspective. Presented as a collage, the words and phrases reflected how strange the women’s experiences were to them and the disorder, unfamiliarity and distress. Emotionally aroused by these words I was helped to consider each woman’s experience from their perspective, so contributing to reflection and the parts and whole process which characterise phenomenological data analysis and interpretation, a part of the study described later in this chapter.

Figure 2: Wordle™: Women’s Expressions
During the study I also searched the internet using Google™ for images which matched the women’s expressions, making collages that mirrored the Wordles™. Unlike the Wordle™, these images helped to imagine the experience the women voiced, drawing me in through an analogue representation, to face what the women encountered and to help place me in their shoes. Sensed was an unwanted separation and the overwhelming presence of an unwanted stranger. Arranged together these images contested who we like our loved ones to be, and the darkness and distrust of realities different from our own. Sensed was the inaccessibility of the women’s loved one; their loved one’s difference, their distance and their separation. Collaged, the images augmented the Wordles™ and the women’s conversations in portraying how strange and frightening their experiences were and what it was like to encounter a co-existing alternative world. The collages of images are not presented in this thesis due to copyright limitations.

These Wordles™ and collages challenged my evolving understandings about delirium and what it is like to experience a loved one during delirium, helping me to reflect and enter deeper into the situatedness of women’s experiences and their meaning. Later, when I used the images and Wordles™ to reflect upon each woman’s experience and the experiences of the women as a whole, they helped me to find the meanings that were being expressed.

**Personal Experiences During My Mother’s Delirium**

As part of the study I committed to describing my own experience as a family member during my mother’s delirium. This encounter occurred during my mother’s admission to large tertiary teaching hospital for acute care. I thought and felt that it was important to document and reflect on my experience and, consistent with van Manen’s (1990) position, felt this experience may be like that of other family members, possibly providing insights into the meaning of their experience. The process of describing and reflecting on my experience was also important in developing deeper self-awareness of assumptions and pre-conceptions, so helping me to orient to the research question and be aware of how I was predisposed to understanding the women’s experiences during delirium. Some of this experience is presented in Chapter 1: Study Introduction.

**Incidental Delirium Experiences**

Very early in the study I became aware that my sensitivity to appearances of delirium had been heightened and that I wanted to capture incidental encounters when they occurred. By their nature these encounters were unpredictable so I recorded them
through descriptive recounts and reflections separate to those completed after
interviews with the women. This allowed me the freedom to react and think about each
appearance before bringing this material to other sources during data analysis and
interpretation. Through this process I kept reflections on interactions with other people
who experienced delirium, primarily in the hospital context and by nurses, and kept
reflections on my visits to the wards involved in the study. Although most of the women
did not visit these particular wards, they represented similar contexts and provided
insights into the places they visited during their loved one’s delirium. Insights from ward
visits are included as background in Chapter 1: Study Introduction and as part of the
participant context and situation in Chapter 5: Prologue.

Popular Literature and Music

Also considered as part of the study were descriptions of delirium in popular literature
and music. My awareness had already been drawn to a novel by Inga Clendinnen
(2000), “Tigers Eye”, however I also located Ladyhawke’s song lyrics for “My Delirium”,
a children’s story called “Delirium’s Party” by Jill Thompson (2011), and a poem by
John Young (2012) called “My Father’s Delirium”. Like the women’s experiences these
sources used words to symbolically evoke the experience of delirium from different
perspectives, contrasting with the perspectives of the women in the study. In the order
of their discovery, each is represented in the following sections with an excerpt
considered poignant and a description of what each excerpt disclosed. These provide
an illustration of how popular literature and music added to study data and aided the
exploration of meaning.

“Tigers Eye” by Inga Clendinnen

As previously noted I was involved in a pilot participatory action research (PAR) study
which explored the care of hospitalised older people who had delirium prior to this
study. As part of the PAR study I was introduced to an autobiographical work by Inga
Clendinnen (2000). In this work the experience of delirium is told through the eyes of
the female author and during many hospital days leading up to and after liver
transplantation, exploring and sharing what it is like to have delirium and to perceive
your family members in a concurrent world. In one passage Clendinnen (2000)
describes feeling panicked by illusions which involve her visiting family members.

…I was watching the mother and child, sucking in great
draughts of comfort from the loveliest of sights, when a tide of
blood surged up and obliterated their faces. I looked at my
grand-daughter, and saw her small bright face was a mask of blood too. My son was, blessedly unaffected. It was all I could do to conceal my panic. I shut my eyes, feigned exhaustion, got them safely out of that terrible place and then yielded, helplessly to superstitious terror. (Clendinnen, 2000, p. 17)

In this passage the author shares her perspective during an illusion and arranging for visiting family to leave as a way of coping with her changing perceptions. Through Clendinnin’s account I became connected to the patient’s world, their experience of delirium and sharing that situation with visiting family; to sense the desire to protect or distance family members, to shield family from the altered world, and the panic which ensues from encountering an unfamiliar perspective on the world. While my interest focused on the experiences of family members, remembering and considering the dyadic nature of relationships and different perspectives during the one situation was important to understanding the meaning of delirium for the women in the study. How their loved one related to them formed part of the women’s situation.

“*My Delirium*” Performed by Phillipa Brown (Stage name Ladyhawke)

I came across the song “*My Delirium*” when exploring the internet looking and thinking about ways the word delirium was being used in popular media. Whilst not an admirer of synthpop⁵, I found the song’s title intriguing. Having been focused on delirium as a health condition, the song served as a timely and valued reminder of delirium’s broader meanings, particularly the juxtapositions of love and pain, certainty and uncertainty, and presence and absence. In this song delirium is expressed as a state endured when separated from a lover and waiting for their absence to be righted, never sure if love will go on. Expressed in the lyrics is how a loved one’s absence pervades what you think and what you feel; how love and attraction can lead to an infatuation or obsession, binding you and manipulating you and your situation. Expressed is a realisation of absence and uncertainty about future presence. How waiting for a lover’s return seems endless, creating an altered state where the burden of singularity is faced. Evident is the experience of absence, a sense of burdened waiting and holding on, aspects of delirium important to understanding the women’s experiences in the study.

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⁵ Synpop is a 1980s popular music genre in which the dominant musical instrument is the synthesizer.
Chorus: Still hanging on (for what)
Can't operate (fired up)
I won't eat and I won't sleep for you yeah
No rest till I (get through)
Coz I'm holding out (for you)
Am I the only one who's insane

Verse: Coz I'm outta my head and outta my self-control
Still here in this quiet room
Deep in delusion sending me over
Outside watch the world go by
Inside time stands still as I wonder

(Brown, Gabriel, Alex, & Robinson, 2008)

“Delirium’s Party” by Jill Thompson

While browsing in a local bookstore my eye was taken by the cover of a children’s book. Pictured on the bright front cover was a child joyously and boldly dancing, wearing a dress covered in figures which represented her brothers and sisters. Titled “Delirium’s Party” (Thompson, 2011) I felt an unease which called to my curiosity about delirium. I purchased the book and over time returned to the book’s cover and title, pausing to ponder the taken-abackness I felt. The title and cover illustrations were a stark contrast to what I had been considering in the study and evoked disquiet about connecting delirium to the innocent everyday lives of children, so revealing my perspective and assumptions. Though uncomfortable, returning to the book caused me to remember that delirium has many meanings and can refer to the joyous rather than dark, to presence rather than absence and to consider what it was about the women’s experiences that made them so unjoyful and different to the experience depicted on the cover of this children’s book. The front cover of this book is not presented here due to copyright limitations.

“My Father’s Delirium” by John Young

The poem, “My Father’s Delirium” (Young, 2012) appeared by chance when I was routinely browsing the Annals of Delirium, a newsletter from the European Delirium Association. Though usually devoted to the latest research here was a description of a man’s experience when with his father and during his post-operative delirium. Reading through the poem I was struck by how similar the poet’s voice was to the women in the study, and yet it was a male voice. I was also struck by how routine can at times be not
routine; how feelings of presence had been replaced by distance and fading; how perfect had become imperfect. Also striking was a hint of familiarity; of the poet being a part of the health care system and finding his experience as a family member somewhat different than expected, becoming emotionally connected to what it is like for patients and family when delirium is present.

In Chapter 6: Study Findings excerpts from this poem are used to introduce each sub-theme, revealing how closely this man’s experience with his father mirrored the experiences of the women in the study.

Images: Delirium In Older People

Finally I searched for and considered images that represented older people during delirium. I was already aware of some images at the start of the study so collected these and added new representations as the study progressed. As each image came to hand collages were developed, clustering depictions of delirium together as a source of inspiration and point for reflection. What struck me about these images was how clearly the artists captured the older person’s altered state of mind; how disordered this was and how foreign this might be to other people, particularly those close to the older person. As noted before the images used in the study are not included here due to copyright restrictions.

While collecting lived experience material I also began to work and dwell on the data, beginning to immerse in, analyse and interpret the women’s lived experience material. In the following sections I describe how this was achieved and how analysis of the data was undertaken to maintain an approach consistent with research based on existential phenomenology and which addressed my research question.

Analysis of Interpretive Interaction

The intent of employing a phenomenological approach to analysis and interpretation of the lived experience data was to try to understand the meaning of the women’s lived experiences from the perspective of the women themselves, distinguishing what it was that made their experience unique and different from other related phenomenon. In this part of the research process van Manen (1990) and Munhall (2007; 1994) argue that researchers need to move beyond the facticity of a phenomenon to the essential quality that grounds the experience and makes it what it is, and without which the

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6 Permission has been granted by the author to reproduce 50% of the poem in this thesis.
women’s experience would not be what it was. In approaching and completing the analysis and interpretation of the women's experiences, the aim of the study and research question acted as a reference point and a reminder that a philosophical stance was needed.

To set the stage for this analysis each interview transcript was read carefully while listening to the corresponding digital interview recording. I made notes in the transcripts to mark speech emphases, emotional reactions such as sighing, sadness or crying and hand gestures. Going back to the recordings provided an opportunity to really listen to the experience each woman shared and each woman’s voice, away from the intensity of the face-to-face interview and any distractions within the interview setting. Several days had passed between the interview and having access to the women’s transcript so I needed to reacquaint myself with each woman’s experience in readiness for reflection and analysis. The intent at this stage was to reawaken each woman’s experience in my mind.

To grasp the meaning represented in the women’s experiences, a sustained period and process of thoughtful reflection and contemplation was then needed, in order to deeply consider the women’s lived experiences and search for obscured meanings (van Manen, 1990). As van Manen’s (1990) approach is grounded in the works of Heidegger, a process akin to Heidegger’s *hermeneutic circle* was used (Van Manen, 1990). Initially this involved attentively reading and re-reading each woman’s interview, re-listening to her speak and her language through the recordings, and dwelling on the recorded experiences to gain an understanding of each woman’s experience as a whole. Important words, phrases and statements were highlighted and explored, all the time asking what statements or phrases seemed particularly revealing (van Manen, 1990). Notes were made to capture my thoughts about meaning, and questions were formed to guide deeper consideration of each woman’s description. At the same time the impressions recoded as interview reflections were consulted and considered, helping to consider and answer the ongoing questions I raised. Where participants used idiomatic phrases and metaphors I explored and reflected on this language while re-reading interview transcripts. I looked for aspects of the women's experiences which might be hidden by their simplicity or familiarity, working to see what the women had placed before me and which I had not noticed.

Dwelling with and contemplating the lived experience of each woman in their context, I was mindful of how my prior experiences, knowledge and emotions might be operating and affecting my evolving understanding. As I worked with the data I questioned myself
and the way that I was thinking about their experience and was reacting. At times the women’s conversations had a profound effect, making it hard not to share the women’s experiences personally. To prevent shared suffering from obscuring understanding time was taken to step away from the analysis.

Over time I went back and forth between parts of each interview and their whole, analysis notes and reflections to make sense of the experience described. I repeatedly asked “What is delirium like for the women?” and “What is going on here?” (van Manen, 1990, p. 86). I wrote, read, contemplated and re-wrote. After several readings of each transcript and contemplating the data over time I isolated and recorded emerging tentative themes as text and, where possible, used the language of each participant or extracts of their interview to describe the meanings I was expressing. Each theme represented the sense made of the experience and said something significant about the experience of delirium for each women within their life context. I also discussed and questioned these themes with study supervisors, all the time being mindful of the influence of my taken-for-granted understandings, and all the time learning to look behind the facts, to recognise undercurrents, to dig down, to uncover and to grasp the meaning of the women’s experiences. These activities together provided opportunities to see meaning and to confirm analysis or consider alternative interpretations, and worked toward the study’s credibility and confirmability. Two illustrations of the data analysis process are detailed in Appendix G.

Rather than being a rigid sequential analysis process, contemplation and reflection on the data and writing were non-linear methods of searching and what van Manen (1990) describes as “seeing” (p. 79). It became a way to access the multilayered and multidimensional aspects of meaning within experience. Integral to this process was clarifying, reflectively appropriating, and engaging in insightful discovery (van Manen, 1990). Reflection, writing, reflection and re-writing were used extensively to isolate and develop phenomenological themes which represent the structures of the women’s experience. These themes move beyond the facticity or appearance of the phenomena to the essential quality that grounded the experience and made it significant to human life. A back and forward, parts and whole process was used to consider and balance study data in relation to contexts and the evolving phenomenological writing. It was important to my approach that I considered whether the themes held a quality which made them essential to making delirium what it is, so for each theme I asked if delirium would lose its fundamental meaning if the theme was removed. As the themes were developed and revised they came together and provided an understanding of the experience of delirium for the women as a whole, the themes becoming “like knots in
the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes” (van Manen, 1990, p. 90).

Writing the Phenomenological Narrative

Phenomenological research tries to bring us closer to the meaning of lived experiences by asking and giving voice to what it is that constitutes the nature of lived experience (van Manen, 1990). Along with reflective contemplation, this is achieved through and writing and re-writing a thoughtful descriptive text which enables others to better understand the phenomena under investigation. Maintaining a strong orientation to the lived experience explored, the phenomenological text is strongly connected to the unique perspectives shared by participants, is rich and thick in the descriptions and language it uses to communicate with the reader, and facilitates thoughtful connections between the explicated meanings (van Manen, 1990). Making clear the qualities that make the phenomena under consideration what it is, the researcher continually works for writing that “reawakens our basic experience of the phenomenon it describes […] in such a way that we experience the more foundational grounds of the experience” (van Manen 1984, p. 65). The phenomenological text developed for this study forms the study findings and is presented in Chapter 6: Study Findings.

Interconnected with analysis of the women’s experiences and branching further to draw on my personal experiences and descriptions in the literature and art, the creation of the phenomenological text was not a simple or linear process. Rather the text was gradually worked and developed through progressive contemplation, reflection, writing, reflection and re-writing, and was intertwined with analysis of all the lived experience data in the study. I went back and forth as I considered each participant’s experience alone and with that of other women continuing to use a parts and whole approach. A tension was felt between what was particular and what was shared. To stimulate further reflection on the meaning of delirium and writing I brought together thematic descriptions from participant interviews and drew upon artistic sources, idiomatic phases, my own and experiences described in the literature. The uniqueness of each woman’s experience and a connection between their life context and meaning gradually became clear. Also clear were similar meanings voiced from within different contexts, insights captured in the evolving text through use of the women’s expressions.

Writing the phenomenological text as study findings needed time and an extensive process of careful attentive writing, reflecting, contemplating, questioning and much re-
writing. This occurred in a self-created atmosphere of uncertainty, an atmosphere in which I reflected, critically questioning and re-questioning the fit of the interpretations I was making, their grounding in the data and the adequacy of my expression. Constantly aiming to uncover layers of meaning, I searched the data in-depth and worked to avoid premature closure of meaning or interpretation and adequate expression of the insights I uncovered.

Analysing the data and expressing my interpretations in writing was not easy; words filled pages but missed what was nuanced within the data: interpretation and meanings were at times lost through barren language and convoluted expression. Although challenging, this meant that some “would be” interpretations were discarded; they were inadequate, superficial, or hollow. I reworked these early interpretations seeking a more sensitive expression of the meaning of the women’s lived experience during delirium. Writing became an activity in which I saw through the factual to what lay behind. When I became “stuck”, I stopped and stepped away from the data and writing for a while, allowing ideas to float within my mind as I reflected with less pressure. At other times insight came unexpectedly or directly and I could “see” and express meaning.

As I worked back and forth with provisional interpretations, themes and the data over time, a strong sense developed that the meaning of the women's experience related to their being-in-the-world with and relating to others. Perceiving others first through our own bodies, we see and are seen. To explore this further, and as noted in the previous chapter, I turned to existential phenomenology and the insights offered by Merleau-Ponty (1945/2002, 1948/2004, 1968) and Sartre (1943/2003). In particular Merleau-Ponty’s (1945/2002, 1948/2004) arguments about the perceived world, and Sartre (1943/2003) and Merleau-Ponty’s (1945/2002) arguments about the lived body and the body of others resonated with the data, spoke to the meaning of family member experiences during delirium and helped me to understand at a deeper level. There was a connection between the intimate nature of family member relationships with their loved one and Merleau-Ponty’s (1945/2002) thoughts on human intersubjectivity, an argument richer and more reflective of family member relationships with their loved one than Sartre’s (1943/2003) views. Both were helpful in coming to understand the changes that family members described in their relationship with their loved one during delirium, in particular Sartre’s (1943/2003) notion of the look, and Merleau-Ponty’s (1945/2002) inhuman gaze. As themes developed Sartre’s (1943/2003) exploration of expect, lack and absence, described more fully in Chapter 3: Guiding Approach, spoke to family member descriptions and informed the sense made of their experiences.
Over a period of many months I worked and reworked my writing and interpretations drawing on the perspectives offered by Sartre (1943/2003) and Merleau-Ponty (1945/2002). These perspectives helped me to progressively understand the women’s experiences from their perspective and in an existential orientation. Analysis and interpretation of study data gradually arrived at one statement which captured the core of the women’s experiences to reveal the essence. Further disclosure of the essence was achieved through related and interconnected themes and sub-themes. Each theme and its sub-themes act as lenses to facilitate deeper and broader access to the meaning the essence portrays. Each is expressed as text and is bound to the women in the study through their experiences in place and time. The essence and themes are common to all the women in the study, be they wife or daughter or whether their loved one was dying or had delirium as well as dementia. The sub-themes describe many qualities shared by all the women but also reveal unique aspects of the women’s experiences, disclosing variant and subtle meanings that are poignant but not always common. In particular absence during delirium is described beside absence experienced from dementia to reveal difference and to gain what van Manen (1984) describes as a view of the “real” meaning of the phenomenon. Two illustrations of the data analysis process are detailed in Appendix G.

Creating a phenomenological text was an integral part of my reflective writing process. It required a style of writing and thinking which, though initially unfamiliar, is hoped will help readers to connect to, and understand, the experience family members when with their older loved one during delirium. Particularly important was commitment to the heterogeneity of the women’s experiences, to the connection between experiences and life context and to the use of language to communicate the meanings of the women’s experience. This commitment called for me to write inclusively of all meanings, including the general and the particular (Munhall, 2007), while also acknowledging that phenomenological exploration and description “is always one interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complimentary, or even potentially richer or deeper description” (van Manen, 1990, p. 31). I also believed that it was important to invite and where agreeable, go back to the women with a summary of the major themes and meaning of delirium based on their experiences. In this study, 14 women shared their experiences of delirium. However, only 9 indicated that they would like to receive, and were sent, a summary of the study findings.
Writing a Narrative on the Meaning of the Study

Presented in the discussion and conclusion to the study is a narrative on the meaning of experiencing an older loved one during delirium for family members (see Chapter 7: Discussion and Conclusions). Shared is a descriptive text which illuminates the meaning and nuances of the phenomenon of delirium for the women in this study, one which has remained true to the unique perspectives the women gave during the study. As suggested by Munhall (2007), within this text there is an emphasis on interpreting the meaning of the study for practice, identifying implications and recommendations for health care. When writing this narrative I was guided by van Manen’s (1990; 1984) notion of connection to practice, a notion that inspires phenomenological narratives that are useful for practice rather than purely examples of theorising. Giving voice to the meaning of the women’s experiences reveals the lived quality and significance of this experience, insights which have to potential to enable health care staff to better understand the impact of a loved one’s delirium on family members. Insights into how we might sensitively support and involve family members in the care of older people during delirium are drawn from these understandings and connect the meaning of delirium for the women to the practice world of health care staff.

Review and Summary

In this chapter I described how existential phenomenology has been used to facilitate exploration of the nature of family member experiences during their loved one’s delirium. Particular attention has been paid to painting a picture of actual activities undertaken when conducting the study and the real life challenges that occurred, highlighting ethical considerations, difficulties experienced in working in a phenomenological way and challenges of implementing planned research activities in clinical contexts, with clinical staff and with family members.

The next chapter presents an introduction to the findings of the study. There I introduce the women who participated in the study and describe their situations. In doing so the setting and background of the women is established, helping the reader to connect with the women as people situated in their life world. Then in Chapter 6 the study’s findings are presented. In this chapter the findings describe the meaning of experiencing a loved one during delirium for family members. I describe what it is like for family members to be with a person they no longer know and what it is like to wait for their loved one to return. In Chapter 7 I present a discussion of family member experiences
during their older loved one’s delirium and the conclusion to the study where implications for health care practices and future research are discussed.
CHAPTER 5: FINDINGS PROLOGUE
Chapter Introduction

Like the prologue to a theatrical performance, this chapter provides an introduction to the study findings. It presents and describes the women who participated in the study and broadly describes where they lived. Initially a description of the women as a participant group is presented, including a description of the location of the study. The description of the women as a group is followed by biographies which introduce each woman and their particular situation. These descriptions contextualise the study findings by providing a background and life context within which each woman’s experience is drawn and has been interpreted.

The Women Who Participated in the Study

All of the participants in the study were women (n=14) and each had experienced their older loved one during delirium, the experience of interest to the study. All spoke English fluently. Most participants were daughters (n=12) of the older loved one, including two sets of siblings who shared the care of their mothers. The remaining two participants were spouses. The ages of the women ranged from 51 to 74 years. Though not excluded from the study, no young adults or male family members participated. Most of the women had retired from work (n=13), however one woman was employed and had teenage children. All of the women were in caring relationships with their loved one prior to the onset of delirium. Thirteen had been caring for their loved one for some time; six were carers supporting their loved one whilst living in residential aged care, four were carers who lived with their loved one and three were non-resident carers of their older loved one. One woman had only just begun caring for her husband at home due to an acute illness. These different caring locations reflect the diversity of settings in which family members care in Australia when older loved ones become frail or unwell. As two sets of sisters participated in the study the experiences described by the women (n=14) pertained to 12 older people. Of these 12 older people, aged between 69 and 100, eight were female and four were male.

All of the women lived in or near a regional city on the coast of New South Wales (NSW), Australia, about 150 kilometres from Sydney. In 2011 the population of their city was 156,533 people, growing at a rate of 0.94% (The City of Newcastle Council, 2011). At this time older people made up 15.4% of the city’s population, with 11.3% of older people aged 70 years and over (The City of Newcastle Council, 2011). Like the city’s whole population, half of the women in the study had been born locally. Three women were born overseas (England n=1, Holland n=1, Germany n=1). The women
were part of the 11.6% of the city’s population (n=14,347) that provided unpaid care for a person with a disability, long term illness or a person who is older in age (The City of Newcastle Council, 2011).

Extending for 187 square kilometres the regional city near to or where the women lived was the economic, administrative and cultural centre for the region (The City of Newcastle Council, 2011). Health services were primarily provided by government funded local health district services, co-ordinated from the city. These health services included three tertiary referral hospitals\(^7\), rural referral hospitals\(^8\) and several district and community hospitals\(^9\) (Hunter New England Area Health Service, 2012).

Twelve of the women in the study visited an acute care ward in the region’s hospitals to be with their loved one at some time during their loved one’s delirium. One woman visited an acute care ward in a hospital located in another state of Australia, and one woman did not visit a hospital at all. Other health services in or near the regional city are provided by not-for-profit organisations, including many residential aged care services\(^10\). Most of the women (n=13) were with their loved one during delirium in more than one setting; some were in acute care wards as well as at home (n=7) or at residential aged care services (n=5). For example Beth [p7] first experienced her husband during delirium at home, then when with him during his hospital admission for intravenous antibiotic therapy. On the other hand, Carmel [p13] first experienced being with her mother during delirium at her residential aged care service, then in the emergency department of the local hospital. In addition, one woman encountered her mother during delirium in the car and later at home.

All the women in the study (n=14) were aware of a sudden change in their loved one (n=12) that coincided with the onset of an acute health condition. Nine women initially encountered their loved one in delirium in the location where their loved one usually lived, be that at home (n=5) or in residential aged care (n=4). Four women initially encountered their loved one in delirium during their hospital admission for planned

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\(^7\) Tertiary referral hospitals in NSW provide care for all but the most complex health needs.

\(^8\) Rural referral hospitals in NSW provide a range of core clinical health services and support. More complex/tertiary services may be provided through formal arrangements with tertiary facilities.

\(^9\) District hospitals in NSW provide local hospital and community health services. Community hospitals provide some primary care services, but predominantly offer low-level emergency, lower acuity and long stay care for their local community.

\(^10\) Residential aged care services in Australia provide accommodation and support for older people who can no longer live at home with family support or/and community support services. Care in these services is usually divided into low and high care based on dependency. In addition, some services are dementia specific. These services have replaced services called nursing homes.
surgery or emergency care, and one woman initially during a planned car trip. Delirium was given to three women as a diagnosis for their loved one. Several of the women described infection (n=8) as the reason given by health care staff for the changes the women noticed in their loved ones presence. Other women thought or were told it was due to surgery, a fracture, heart or bowel problems or the environment. Most women (n=11) described experiencing changed behaviour in their loved one, such as restlessness, combativeness, wandering and hallucinations, changes that are consistent with hyperactive delirium (see Chapter 1: Study Introduction). Two women described experiencing changed behaviour consistent with mixed delirium, such as at times being quiet and at others hallucinating and trying to climb out of bed. Several women (n=5) experienced delirium that persisted for more than a month. The loved ones of two of these women were assessed as needing palliative care during their hospital admission and after the onset of delirium. One woman’s loved one returned home with persistent delirium after approximately 4 months in hospital. All the women were with their loved one on more than one occasion during their delirium. While eight women experienced one episode of delirium, six encountered recurrent episodes.

Eight of the women had older loved ones who experienced delirium as well as pre-existing ADRD (n=7). These eight women recognised that their loved one’s behaviour during delirium was very different to their usual behaviour during early to moderate ADRD. None of their loved one’s had late dementia nor needed dementia specific or high care residential aged care services. Only one lived in residential care at the time of their first episode of delirium. Of the loved ones who had pre-existing dementia (n=7) only two were alive at the time of the women’s interviews; one lived at home with his wife and one lived in low-care residential aged care.

Most of the women (n=8) took part in the interviews within a year of encountering their older loved one during delirium, one woman participating during her husband’s hospitalisation and delirium; a difficult time in her life. However, more time had elapsed since their loved one had experienced delirium for the other women (n=6) in the study, ranging from two to nine years. Though much time had passed these women’s recall of their experiences remained vivid and their descriptions were detailed. Eight women participated after the death of their loved one (n=7) and, though time had passed, recalling their experience evoked sadness.

Though the previous description profiles the women and their older loved ones broadly, embracing a phenomenological approach to exploring lived experience invites the researcher to have an interest in each person who shares their experience, including
the time and place in which they experienced the phenomenon under investigation (Cohen et al., 2000). Over the time I was involved with each woman I gained insights into their day to day lives, family relationships and what it was like for each of them to live through their loved one’s delirium. Also important were insights gained from demographic details included on the consent form and those gained from hospital ward visits. Many of these insights are shared in the following biographies, providing a sense of each woman’s identity, life context and situation. These insights ground the study findings to the world in which the women lived, a connection important to phenomenological investigation (see Chapter 3: Guiding Approach), and for understanding the situatedness of the meanings described in Chapter 6: Study Findings.

**Participant Biographies**

The discussion now moves to provide biographies which introduce each woman and their particular situation.

**Ann (Participant 1)**

At the time of the study Ann was 68 years old. Each time we met she carried a hand crafted bag containing things she hoped to enjoy with her husband, Al; the newspaper, a pack of cards, Sudoku games, and food from home. Her face showed signs of weariness and she would often cry when talking about Al, their family or their new home, but particularly when she told of her experiences with Al during delirium; when he would invent a fantasy world of imaginary animals or people and wanted to drive his bed around the ward as though a truck, asking Ann to help change gears. He’d throw his hands around, try to escape from his bed and talk about people that weren’t there or events that weren’t happening.

Ann had a long-standing marriage to Al and together they had raised their four children; three sons and one daughter. In earlier times Ann and the children had followed Al’s work and lived as a family in many small and large Australian towns. Al had worked in many roles, including truck driver and white goods electrician. The boys had entered the Army and much of their family lives were now flavoured by Army events. Now the children were adults and mostly lived close by. They were frequent visitors to Ann and Al, especially the three boys.

At the time of the study Ann and Al had only just moved into a new home. Together they were deciding where paintings were to be hung and what belongings would be
placed in which new room. A favourite painting of Ann’s, of sunflowers, was difficult to
place. Much attention had been paid to the computer so Al could continue his
genealogical work, particularly his international research. They were still in the process
of unpacking when Al became unexpectedly ill with severe knee pain. After a couple of
days Ann knew Al’s problem was serious; he just wasn’t interested in doing the things
he loved. She took the decision to call an ambulance; Al uncharacteristically agreed.
Her husband previously had heart bypass surgery and intermittent pain associated with
claudication and Ann thought what was happening was somehow related. When Al
got to hospitalAnn was unaware that her husband’s pain was from an infection, one
that would necessitate emergency limb amputation and her husband battling for his life
for weeks.

During Al’s hospitalisation Ann visited daily; for four months, arriving at about 11.00am
each day and leaving after she settled Al for the night, usually after 7.00pm depending
on how confused he was. During the day she would take a break, often finding an out
of the way spot so staff passing by would not stop and disturb her time alone. During
her life Ann developed a love of reading; a pastime that provided distraction and
comfort during her many hospital visits.

At the time of the interviews Al’s condition had stabilised and Ann visited her husband
on the orthopaedic ward, a place which had an atmosphere of calm busyness as
patients were moved on beds, staff walked deliberately down corridors, equipment was
transported, medical officers arrived in teams, call bells buzzed, charts clattered and
multiple phones rang. The entry area seemed to be a hub around which care activities
were co-ordinated and staff gathered; a staff zone away from the patients they cared
for. Patient care areas were off to the sides of the hub, and were largely invisible from
the ward entrance.

The focus for care on Al’s ward was orthopaedics or trauma care\textsuperscript{11}, and it was a typical
acute care ward rather than a specialty delirium care unit. Delirium was a known
problem for older people on this ward and health care staff talked about delirium as
being a routine experience, particularly when patients were admitted after a fall at
home or after a surgical procedure. Often the older person would be located in a room
near the nurses’ station where observation could be maintained, an experience Ann
and Al had for a while. Noise, artificial light and the constant movement of staff were
persistent features. Sometimes a “special” nurse was allocated to monitor the patient’s

\textsuperscript{11} Al’s ward was the orthopaedic ward participating in the study and was visited by me throughout the
study. Hence more is known about this setting as the location of Ann’s experience than the settings of the
other women’s experiences.
condition and manage disruptive behaviours but not so for Al and Ann. Ann wasn’t sure why but surmised that it was because she stayed with Al. Sometimes staff would walk around the ward with the older person, play cards or read the paper, activities which Ann took on when visiting Al. Family members would visit other older patients with delirium, some spending each and most of the day with them, others visiting only for a while.

In recent years Ann’s own health had declined, though at the times interviewed Ann felt her health was stable and that she needed to be strong to help Al. In the past Ann experienced a heart attack and was consequently treated with a stent. Unfortunately she then had a mini stroke and temporary renal failure ensued. She had needed haemodialysis for five months and now watched her renal function closely. Al had been helping her out at home but their roles reversed when Al became so sick. After many weeks in hospital and though Al’s delirium persisted, Ann took Al home to resume their life together in their new home. It was at this time that Ann exited the study.

Sally (Participant 2)

Sally was 62 years old, carefully dressed and reserved each time we met. She was a local woman and had lived in the one location all her life. When we first met she carried with her a set of photos and a report from her father’s gerontologist. The photos were of her father and she referred to these with pride during our conversations, often highlighting his achievements, including turning 100 years of age. Although she would often smile, her eyes would become teary as we talked about her father and what it was like for her during his episodes of delirium; when he would lash out and slap her, pull at the restraints that held him in his chair, constantly fumble and pull at the buttons on his pyjamas or try to take his pyjamas off. Sally’s father passed away eight months before the interviews from heart failure.

Though Sally now lived alone in the family home, she had been a live-in carer for her father for 11 years. Prior to this Sally worked full time. Once she had more time at home she realised that her father needed more assistance and supervision than she had noticed when working; he had been living alone for several years after the loss of his wife, with minor support from Sally. Having made the decision to leave work Sally arranged to receive a carer’s pension which, together with her father’s work pension, provided enough income. Sally’s two married brothers were supportive and provided help whenever she needed. Though her father had early dementia Sally was able to leave him during the day and would often go for long beach walks. She also
volunteered for Meals on Wheels each Friday; she would leave a note on the kitchen table for her father, and her neighbours would keep an “eye out” in case he needed anything.

Sally’s father lived to experience his one hundredth birthday. She was proud of him being the oldest surviving employee of a major company and being well known in the community for his participation in a choir and church. As an active man he enjoyed playing tennis to the age of 95 years. He had only recently failed his driver’s test and lost his licence. Many hours were spent sitting and listening to music, pottering in the garden or tinkering in his shed. He was a well man who had early dementia and past cancer of the bladder floor. About once a year he would get an infection, particularly a urinary tract infection, and would become aggressive and go to “do da land” until the infection was treated.

Occasionally Sally would arrange for her father to go into respite care, including the occasion leading up to her father’s death. In respite her father developed a urinary tract infection and, when disoriented going to the toilet, had a fall which necessitated a trip to the local hospital emergency department and sutures in his scalp. During this admission her father “had it” [delirium] one last time and was hallucinating and wandering. The nursing staff would put the bed sides up and, when out of bed, tie her father into the chair. Sally was mainly with her father during meal time so she could help him eat. If she couldn’t go, she would arrange for another family member or neighbour to take her place. When with her father she would tell him about people and events or point out things on the television. But mostly she would sit quietly with him and hold his hand so he would stop pulling at the buttons on his pyjamas. The nursing staff would encourage her to leave if her father was asleep.

The decision to have her father admitted to a residential aged care service was made by her brother and his wife. Although relieved that the decision was made, Sally knew that her father did not want to be in a “nursing home” and felt he would die if he was moved. Her father died during his first day in his new home.

**Lyn (Participant 3)**

Lyn worked till she was 61 years old and now, at 71 years, lived alone in her own home. She was born locally, had been married twice, but was now divorced. Her daughter lived in a nearby suburb and had two small children. They visited often. Her 37 year old unmarried son lived an hour and a half away and provided her with lots of support.
Lyn had been unwell. She was being treated for recurrent cancer and had recently had a radical neck dissection and radiotherapy. She found she was now very tired and chose to focus on enjoying her life. Because of her past live-in carer role for her mother and her own illness she had not been able to have a holiday and was looking forward to going overseas with her oldest son in the next year, provided she was well enough. She had always wanted to go to Europe.

Until recently Lyn’s mother either lived in her own home or with her. Lyn had always had a close relationship with her mother, but thought that her carer role started when her father died. Lyn provided intermittent care at her mother’s home and arranged community services to help with meals and the garden. Though her mother was “a little bit dotty”, Lyn limited her time with her mother as she felt it would “pull her down” and she needed to keep her emotional strength to be with her own family. After several fainting episodes her mother’s medication was changed and a pacemaker inserted, improving her health.

Lyn recalls her mother going into delirium when she had bladder infections. At the time of the interview her mother had not had one for a couple of years, however in the past she would get very sick. She recalled one day when she found her mother in her home and really unwell. She called the ambulance and they went to hospital. There Lyn experienced her mother hallucinating; she was trying to get the spiders or insects which were climbing on the windows. This was very unusual and her mother was diagnosed with a bladder infection. After this Lyn knew when another infection was present and knew to go straight to the local doctor for antibiotics. This would head off the hallucinations and reduce how sick her mother became. Once the infections past Lyn felt her mother would go back to her normal self again.

Lyn’s mother came to live with her when she was 92 years old. Caring for her at home lasted for about two and a half years, her mother then moving into a residential aged care unit. In hindsight she thinks she left this change too late but felt she needed to build up her strength before the move happened; her mother could be very demanding. Though more than three years had passed between Lyn’s last encounter with delirium and when she participated in the study she would, at times, become upset and cry when describing what happened. At the time of the interview Lyn’s mother continued to live in a nearby low care residential aged care unit. Due to her own failing health Lyn participated in one interview.
Cathy (Participant 4)

Cathy was 70 years of age when interviewed and lived with her son in an town house. She had battled over many years with illness, primarily lung disease. Her hands were also very deformed from arthritis. She had been married; however, her husband had taken his own life many years previously, after a long battle with schizophrenia. Cathy recalled visiting him in a secure psychiatric unit and being distressed by seeing him in a “straight jacket”\(^\text{12}\). For Cathy there were similarities between these experiences and what she encountered in supporting her mother. Cathy would become upset during the interview, her eyes welling with tears when she talked about her mother’s confronting behaviours during delirium; when she was “off with the pixies” and talked about people being present who were long dead and constantly tried to climb out of her bed. When she was aggressive and would push, shove and slap Cathy or anyone trying to care for her.

Cathy articulately told of her many business ventures and enjoyment in running private haberdashery and telecommunications ventures. She particularly enjoyed the company of other women who visited her haberdashery store and learnt how to knit, crochet or sew; she thought it was like an early “women’s shed”. She was now officially retired, though she was just as busy helping her son to run his business.

Cathy, though unwell herself, supported and advocated for her mother. Aged 97 years, her mother was living in residential aged care nearby. As her mother’s eyesight progressively failed she moved from her family home to a low care unit, where she managed very well. Her mother was an articulate woman who kept to herself but kept up to date by listening to the radio and television. She was well but had tunnel vision from glaucoma. She did not have dementia. To help provide an interest Cathy would ensure a supply of talking books\(^\text{13}\). At times Cathy would laugh and claim that although she was supporting her older mother, she herself was old.

Cathy first encountered delirium about 2 years before the interview. From then delirium became a regular part of life, occurring whenever her mother developed a urinary tract infection. At these times Cathy’s mother would be moved from her residential aged care unit to the local hospital. There Cathy experienced difficulties in getting effective antibiotic treatment for her mother, often resulting in the infection advancing. When this

\(^{12}\) *Straight jacket* is an old term used to refer to a long-sleeved jacketlike garment used to bind a patient’s arms tightly against their body to restrain their movement. In Australia these jackets are not used in care of the older person.

\(^{13}\) *Talking books* refers to books, magazines and newspapers produced in audio format.
happened intravenous antibiotics would ultimately be administered and her mother would quickly return to her usual self, not knowing what all the fuss was about. She would return to her residential care unit each time. However, with each passing episode, her mother’s delirium escalated. The most recent encounter, just 3 months before interview, was the most severe; at the time Cathy was advised that their mother would not live. Despite this Cathy knew that her mother would recover once the antibiotics worked. She had seen it before and new from experience that this was how her mother’s delirium unfolded.

**Sharon (Participant 5) and May (Participant 6)**

Sharon and May were siblings who shared the care of their mother; Sharon a live in carer and May living just a few doors down the road.

At the time of the interviews Sharon was 68 years old and living in her own home. She had lived in Sydney and worked in real estate, mainly in the eastern suburbs. Well before her mother’s death, Sharon had retired and relocated to her current home. She then became a live in carer for her mother as, at the age of about 97 years, her mother’s failing eyesight necessitated she no longer live alone. Prior to coming to Sharon’s home she was treated for cancer and assisted to self-care with failing vision. She would however walk for long periods on familiar local beaches and amongst the coastal vegetation.

The decision to care for her mother reflected a promise Sharon had made to her father. The change in living arrangements prompted additions to Sharon’s home, including balconies for her mother to enjoy. Also changed were daily routines and freedoms. The home based caring role was shared with her older sister May, who lived in the same street and was 74 years old at the time of her interviews. They were well and very capable of managing their mother’s health needs as these progressed, in the later period with the assistance of community services. Both sisters were devoted to their mother. About three years had passed between their encounter with delirium and when they participated in the study. Their mother, the older woman for whom they both acted as carer, had passed away two years prior, at 102 years of age.

At their request Sharon and May were interviewed together. They described their mother as very British and like the queen mother. She was known to the neighbours as “the duchess” and within the family as “her maj [majesty]”\(^{14}\). She was known to speak

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\(^{14}\) *Her maj [majesty]* is a colloquial term used by the family to say that they thought their mother acted like she was the Queen and expected to be treated like her; like royalty.
her mind and to carry a particular handbag; “the royal handbag”, a habit continued when in her daughter’s care. Their mother was particular about her routines, even when in Sharon’s home. Sharon and May found her very stubborn. Once living with her daughter she had a tendency to “fall”, often associated with hypotension and necessitating a review of her medication. On one occasion she fell and broke her arm. Though their mother had early signs of dementia she was well able to interact with her daughters and would, together with her daughters, complete a crossword each day; even solving the nine letter word problem just before the stroke that finally took her life.

During a routine admission to hospital for the removal of a skin lesion and skin graft, their mother became delirious. At the time their mother was 100 years old, legally blind and also had an episode of bronchitis. Sharon and May stayed with her until entering the theatre as she was anxious about the surgery. After the surgery the nursing staff in recovery called the sisters into the ward to calm their mother down, though they did not explain what was going on. Their mother was trying to get out of bed and was hallucinating. She was very frustrated that no-one was stopping the children from running up and down the ward and throwing marbles under her bed. Particularly troubling was the absence of her handbag and the different night gown she wore; one that opened down the back.

Though their mother’s discharge was earlier than planned and though she was still hallucinating, Sharon and May took their mother home and resumed caring. She remained in their care until, about 12 months after her surgery, their mother suffered a stroke. She was hospitalised and, five weeks later, passed away.

Beth (Participant 7)

Beth, aged 62 years at the time of the interview, lived in a modest suburban family home with her second husband James. Between them they had four children, a son and daughter each. Her husband’s daughter lived in a nearby rural town and his son in a nearby city. Both of Beth’s children lived nearby. Beth described their family as close, but not that close.

Beth had a reserved demeanour and had been a live-in carer and wife since James, then aged 79 years, developed dementia. They had met when working and volunteering in a palliative care unit at a local hospital. Prior to this James had been in the Royal Navy and later the Royal Australian Air Force. They shared a love of reading and words, a passion seen in their extensive book and dictionary collection. Before the first interview Beth was reading a novel to James, sharing the story as his eyesight was
so poor he could no longer read. He could however follow and understand the story by listening. Reading together now had a special place in their lives. They also enjoyed walking together, going out each day, even in light rain. James also played indoor bowls each week, enjoying the social side over the competition. For Beth, this time alone offered some respite; she was finding James’s care more constant.

Beth’s encounter with delirium began suddenly one night at home when James was unwell with a fever; a fever Beth was unable to control with paracetamol. During the night she found James urinating in the bedroom cupboard and knew that something was different and wrong. She called the afterhours GP service and, after being triaged, James was taken by ambulance to the local emergency department. He was diagnosed with pneumonia and delirium, and was admitted for several days for treatment with intravenous antibiotics and an indwelling catheter. While James stayed in hospital Beth visited for long hours as his confusion was far worse and different to at home; he was talking gibberish, would get out of bed for no reason, go to the bathroom and then not know what to do. Beth feared that the nurses would not keep a close enough eye on him to ensure he didn’t become lost and that he was safe. Although James talked in English Beth couldn’t make out what he meant and nothing Beth said made any sense to him. Unlike at home James was “off with the pixies” during delirium.

Beth was relieved when, after 3 days in hospital, she negotiated to have James discharged home on oral antibiotics, with support from their trusted general medical practitioner (GP). James started to return to being himself before going home however, after time at home and resolution of the pneumonia, he returned to being the person he was before.

**Janine (Participant 8)**

Janine was 62 years old when we met for the study. While she lived locally her immediate family were born in Holland and had come to Australia to live before Janine was born. Janine often became upset and teary when telling her experience, stopping the interview several times when her emotions took control. Janine would become embarrassed and upset when she talked about her mother’s confronting behaviours and imaginary world during delirium; when she talked about the Nazis as though they were in the room, tried to escape by climbing over the sides of her bed, ran around without clothes on and struck out at the family and nursing staff. Despite Janine’s sadness she wanted to continue to tell her experience with her mother. Approximately 6 months had passed between Janine’s experience and when she participated in the
study. During this time her mother had passed away and had spent the last weeks of her life in a high care residential aged care service. Her mother was 83 years of age when she died. Due to changes to family circumstances Janine participated in one interview.

Janine lived with her immediate family and had, in the past, supported her father to care for her mother in their marital home. This meant frequent car trips to a nearby town, usually whenever Janine felt that something was wrong or when her father needed help. Janine recalled that her mother had become mildly confused over time, often having these changes hidden by her father. A specialist assessed her mother and medication was prescribed for early dementia, however Janine felt the medication didn’t help.

Janine recalled two specific times when her mother became acutely unwell and delirious. One was several years earlier when her mother was admitted to hospital with an acute cardiac condition. This time Janine noticed that her mother was hallucinating about the Nazis and had various states of lucidity; she was “coming in and out”. The second more recent episode was when her mother fell, broke her arm and needed hospitalisation. She was more confused and was “off track”. The hallucinations about the Nazis recurred and others appeared. Physical restraints were used during this admission, but these only made her behaviour worse. Janine felt the nurses didn’t want to care for her mother as she tried to escape from the ward and they felt she was aggressive towards them. From the hospital Janine’s mother was transferred to a high care residential aged care unit. It was there that she died 3 months later.

**Pat (Participant 9)**

Pat’s mother had passed away just 3 months before her first interview and her loss was still raw. Pat, along with her two brothers, had been supporting their mother for some time as she had multiple health problems and was living alone in her own home in another state of Australia. More recently her mother had moved into a low care residential aged care facility; she was finding it physically difficult to manage at home on 24 hour oxygen (for pulmonary fibrosis) and felt that her health was deteriorating; she had “hung on” at home for as long as possible. Her mother had endured many health issues all her life, including a thyroid problem, and was in constant pain. However, Pat felt this never stopped her mother in the past; she was always out and about, very social and just took a lot of pain killers so she could keep going. Pat described her mother as not having a history of dementia and normally quiet bright; she
was forgetful but not confused. To Pat she was normally “with it”. Pat’s support continued after her mother’s move, flying back and forth between her home and where her mother lived. Pat’s parents had been divorced for a long time and Pat’s father had lived near her in NSW. He had passed away several years prior. Leading up to her experience of delirium, Pat received a phone call from one of the care staff at the residential aged care facility to say that her mother was being referred to the hospital because she had a problem with her bowel; the facility GP feared there may be an obstruction. Pat had seen her mother about ten days before the phone call and found the change in her mother’s health unexpected. Her brother visited their mother in hospital and phoned Pat to say that she was different; the doctors advising that her mother was experiencing delirium, and that her bowel problem was resolved. Pat flew down to see her mother in hospital, unsure about her mother having delirium; this condition was a shock. To Pat delirium was somebody who was raving and talking irrationally, something she didn’t consider possible for her mother.

Pat would become sad and upset when she talked about how her mother was during delirium; how her mother went from being peaceful and at rest, to “out of it”, thrashing around in the bed and putting her arms over the bed rails trying to escape. Though it was hard to be with her mother when she was like this, Pat stayed and provided support, doing practical things related to her care. During this time Pat questioned whether it was her mother’s pulmonary fibrosis that was causing the problem or something else. Also during this time her mother’s condition deteriorated and Pat was advised that her care had become palliative. It was important to Pat that her mother return to her residential aged care facility to die; to die peacefully in a loving home like environment like her father had done. Pat arranged for this to happen and helped transfer her mother back to her home in the residential aged care facility. Pat had stayed with her father during his palliative care and was present at the time of his death. She wanted to do the same for her mother, so arranged to stay. Soon after the transfer Pat’s mother passed away, at the age of 88 years. Pat was out of the room at the time she died.

Since the death of her father Pat had worked as a volunteer at the residential aged care service where her father had lived and where he passed away; she called the bingo every week. She enjoyed this role, feeling that it both gave to her and to the residents. Pat also supported her brother who lived nearby. She described her brother as suffering greatly from alcoholism and chronic schizophrenia, describing multiple hospital admissions and contact with the mental health team. Pat had recently met a new man and was enjoying having him in her life. She was 63 years of age.
Brooke (Participant 10)

Just over two years had passed between Brooke’s encounter with delirium and when she participated in the study. Her mother, the older woman for whom she acted as carer, had also passed away during this time. When Brooke shared her story she was 60 years of age and lived in her own family home. She had been married twice but had also divorced, now enjoying having her son and his wife living with her. Her daughter lived nearby.

In the past Brooke’s mother had lived alone in her own home nearby. She described her mother as very fit, having endurance beyond her own, and as “a real lady”. She had, however, lived with heart failure, hearing impairment, cataracts and glaucoma. Brooke also noticed that her mother was becoming forgetful and so she began cooking for her and assist with other daily activities. At times she became very frustrated with her mother’s confusion and her inability to remember instructions. When Brooke made the decision that her mother was to move in with her, her mother accepted and her siblings were supportive (brother and sister). They purchased a new family home with a “granny flat” and all moved in. At this time Brooke’s mother managed well living in the granny flat but Brooke still cooked and, at that time, kept working during school hours as a personal assistant. Once settled in Brooke’s home her mother would love to go into the garden and would help Brooke by bringing in and folding the clothes. As her mother’s confusion persisted and her own marriage fell apart, Brooke made the decision to leave her husband and move back to her original family home with her mother. There she acted as a full time carer. Once at this home, Brooke’s mother liked sitting and listening to her old world music, having friends over for a coffee and chat, or travelling in the car on holidays with Brooke. A favourite companion was her cat, who followed her or curled up next to her when sitting on the lounge on the veranda. During this time Brooke and her mother had a trip away, taking her mother with her in the car to visit family in Queensland. It was on this car trip that Brooke encountered a sudden and scary change in her mother’s behaviour, a change which the general practitioner attributed to a urinary tract infection. Brooke was shocked by her mother’s confronting behaviours during delirium; when her mother suddenly “lost the plot” and tangled herself in her seatbelt or kept taking it off, tried to get undressed as they drove along and wandered away from Brooke at the petrol station. Later, when her mother’s infection had been treated, Brooke’s mother returned to how she was before the infection, as though nothing happened.

Granny flat refers to accommodation within or added onto a house which allows an older person to be close to family members but live semi-independently.
Due to her circumstances, Brooke participated in one interview. However, her initial description had depth and was extensive.

**Betty (Participant 11)**

Betty shared the care of her mother with her older sister, Iris (see participant 14). Aged 51 years at the time of her interview, Betty was the youngest woman participating in the study. On the day of the first interview she had seen her teenaged children off to high school. Betty lived with her family, worked and, along with her sister, supported her mother. She appeared happy with her mother’s current residential aged care service and trusted the care provided by both the nursing staff and the GP. She was relieved about this as an earlier aged care service had, in her view, been inattentive to her mother’s needs. Before her mother’s admission for care, Betty had supported her mother to live in her own home, with her, and within a self-care unit. She described caring for her mother in her own home as a hard time though short; her mother decided to relocate into a self-care unit as she did not want to feel like a burden on her daughter. This was a good outcome for both Betty and her mother, with her mother’s self-care improving once settled. At the time of the interview’s Betty’s mother was 88 years of age.

Identifying herself as her mother’s co-carer, Betty often referred to her decision making responsibilities, especially related to her mother’s acute care when her condition deteriorated; a frequent event due to multiple health conditions. There was a sense of burden and uncertainty when she spoke; she was finding it difficult to interpret her mother’s needs when she was acutely unwell and acutely confused. Betty’s brother and sister helped with their mother’s care and, although they were supportive, Betty felt that caring and decision making were largely her responsibility.

Betty had only recently witnessed changes in her mother which she thought were from dementia. However, over a longer period of time, she had experienced many episodes of delirium attributed to recurrent urinary tract infections; delirium was a constant possibility. Delirium was also a familiar word for Betty. In her childhood she had heard it used in association with her brother when he was in hospital with a fever. Though not allowed to visit during the fever, she recalled her mother describing how he was trying to catch imaginary butterflies above his head. When Betty encountered a sudden change in the way her mother was, she thought it was the same as her brother. Her finely tuned understanding of what was normal for her mother helped her to know that something was not right and to question why and seek help. Betty would become upset
when she talked about her mother’s behaviours during delirium; when she was not herself and acted oddly, as though in some sort of a daze, walking around half asleep, and then all of a sudden awake again. Only some of her mother’s episodes of delirium required hospitalisation.

Gemma (Participant 12)

About six months had passed between Gemma’s encounter with delirium and when she participated in the study. She had been helping her mother and father to live at home when her father’s heart began to again fail; some 27 years previously he had undergone open heart surgery. Late one Saturday night she recalled helping him to bed and deciding to call the ambulance to take him to hospital. While Gemma had noticed slight cognitive changes in her 87 year old father, he did not have dementia. However, on this night Gemma became aware of a sudden change in her father and the presence of delirium; he was hallucinating and seemed confused about where he was and what he was doing.

During his hospitalisation, later transfer to temporary care and finally to a high care residential aged care service, her father’s hallucinations became worse. He thought that the ward lights were part of a construction site and that the staff were workmen, that animals were flying around the room and people were there to cut his throat; to Gemma he just dreamt up things, or things happened in his head that weren’t really happening. She also noticed that his confusion fluctuated, often less apparent earlier in the day. Though Gemma understood what was happening to her father she also found that at times his responses were embarrassing; she recalled him repeating a childish rhyme about his doctor and feeling embarrassed. He would say “Dr Boo did a poo”. Over and over again and would not stop. She found the hospital staff reluctant to speak about his acute confusion, his continued deterioration and his possible passing. She found it disturbing that her father would at times act angrily towards her, perhaps she thought, because she had been the one to try to have her parents go into respite care. Her father passed away from heart failure after only being in a high care residential aged care service for one week. This was about four months before her interviews.

Gemma, aged 60 years, lived near her parents with her second partner. With the help of her sister and brother they had supported their mother and father to remain in their own home, at times spending many hours there on a single day. She recalls her mother as being unwell with many illnesses, but doing most of the household chores and being focused on her father’s needs. Whilst Gemma had tried to arrange
community based support to help her mother care for herself and her husband, this assistance was always rejected. When her father was in hospital the family would visit each day and spent long periods with him and their mother.

**Carmel (Participant 13)**

Carmel was the youngest of three daughters and, as the only one living close to her mother, had become the one who provided support in the later stages of her mother’s life. At the time both older sisters lived more than two hours away and Carmel found it difficult to relate to her unwell older sister. Carmel, who was 62 years old when interviewed, was married and had a son. Carmel had worked as an administrator in a doctor’s surgery and felt she had some health knowledge and was able to speak out on behalf of her mother. She described her mother as being widowed for 17 years and as loving. Her mother had experienced ongoing problems with heart disease and, when she was about 80 years old, developed early signs of dementia. Over time Carmel noticed gradual changes in her mother from dementia, eventually leading to her relocation into residential aged care, at about 85 years of age. Her mother’s voluntary move was a relief for Carmel, who visited often.

Since her mother’s admission to residential aged care Carmel felt her mother’s life was uneventful. This was unless she developed an acute illness, like a urinary tract infection. Then her mother changed so suddenly that it was like being with an erupting volcano; her eyes would become cloudy, she would have a total loss of orientation, become angry and develop hallucinations, and delusions. Often her mother required hospitalisation. When telling about these experience and remembering her mother’s delirium Carmel became sad and embarrassed; experiences where her mother swore and talked loudly to the nurses and doctors, fought them and tried to escape from the bed by climbing over the sides, running around and screaming for help from the police. As Carmel says, generally “throwing haymakers”.

Carmel and her sister were present with their mother when she peacefully passed away from heart failure, in her room in the residential aged care facility. She felt that her mother had clearer thinking before she died and she found this a happy way to remember her. Carmel’s mother passed away 9 years before her involvement in the study. Her last experience of delirium was during one of her mother’s hospitalisations, six months before her passing. Despite the lapse in time Carmel spoke in depth and at length about her repeated experiences with her mother during delirium.
Iris (Participant 14)

Iris shared the care of her mother with her younger sister, Betty (see participant 11). She had encountered delirium or, as expressed by Iris “anxiety episodes”, many times when a co-carer for her mother. She felt they were a constant possibility due to her mother’s recurrent urinary tract infections. Iris would become sad during the interview when she talked about her mother’s “anxiety episodes”; when she was so confused she would ring on the phone over and over, or call the ambulance. When she would forget who Iris and her sister were or what familiar objects were. When she would get so agitated they had to stay with her for hours and calm her down.

Iris had only recently noticed memory changes in her mother, changes which were assessed by a specialist as being minor and not related to dementia. She described her mother’s health as poor; she had many chronic health conditions including diverticulitis. At the time of the interview’s Iris’s mother was 88 years of age.

Iris, with the help of her younger sister and at times their brother, supported her mother who was then living in a high care section of a residential aged care facility. At the time of the study they visited every day and assisted their mother to eat. Prior to this, Iris’s mother had lived in her own home, with her sister Betty and then within a self-care unit. The move from the self-care unit to high care became a necessity after Iris’s mother had been in hospital and sustained a minor head injury. Though she expressed comfort with the quality of the care currently provided to her mother she also expressed concerns about the events which necessitated her mother’s move from low care to high care and about the care provided in by a previous facility. Important to Iris was care which promoted her mother’s dignity and comfort; during her life her mother had been particular about her appearance. During her caring role for her mother Iris had come to learn that acute changes in her mother would happen when she developed a urinary tract infection, something that happened often but could be reversed. For Iris, this problem did not seem as major as other health issues her mother had; other problems that went on and on, and became worse.

Iris, aged 65 years at the time of the interviews, lived with her husband. She had moved from Europe to Australia when she was young, recalling her travel by boat to Australian shores. Her son had passed away several years before her interview. Due to family circumstances Iris participated in one interview.
Review and Summary

This chapter has acquainted the reader with the women who participated in the study. Initially a description of the women as a participant group was presented. This was followed by biographies which introduced each woman and their situation. These descriptions have provided a life context and background within which each woman’s experience was drawn, was narrated and has since been interpreted. In the next chapter the findings of the study are presented.
CHAPTER 6: FINDINGS
Chapter Introduction

This chapter presents the findings of the study. In keeping with van Manen’s (1984, 1990) orientation to thematic phenomenological analysis, the essential nature of the phenomenon investigated by the study is described first, followed by a description of the themes and sub-themes that constitute the experiences of the women in the study. Whilst Van Manen (1990) suggests several approaches to presentation of phenomenological research, a thematic approach focuses on creating a sense of organisational form by making visible the essential nature of the phenomenon of older person delirium for the women in this study, and then systematically laying open the themes and sub-themes that constitute and speak to this complex phenomena to reveal its overall structure (van Manen, 1984, 1990). Whilst explicating each theme and sub-theme various exemplars from the women’s experiences and details from their situation are included to illuminate nuanced meanings and to connect the themes and sub-themes back to each woman’s life context (see Chapter 5: Findings prologue).

The essence of the women’s experiences and themes are common to all women who participated, whether they be a wife or daughter, or whether their older loved one had dementia or was dying. The sub-themes are at times shared by all women and at others only by some. For example, the sub-theme Living with a stranger is experienced by all women whereas On thin ice is particular to women who encountered their loved during recurring episodes of delirium. In addition, subtle variations to meanings are woven through the sub-theme descriptions. These variant meanings are in keeping with the sub-theme but are not common to all the women. The sub-themes also reveal nuances of each woman’s world, particularly their relationship with their older loved one. These nuances make experiencing the phenomenon what it is for each woman. Taken together, the findings communicate the meaning of being with a loved one during delirium for the women in this study.

Consistent with having adopted a thematic approach, a textual linear and sectioned format has been used to present the findings. This format is not intended to convey categorisation, discrete margins or a timed sequence. In this study the women’s experiences during delirium were complex. Like a bird’s nest, each comprised overlapping and intertwining twigs or dimensions that wove together to shape and form their experience as a whole. Reflecting this complexity, the thematic descriptions presented here weave together, a feature which is particularly evident between the sub-themes Facing a loved one’s absence, Living with a stranger and Waiting for a loved one. Adding to the meanings communicated in the findings, excerpts from John
Young’s (2012) poem titled “My Father’s Delirium” 16 are used to open each sub-theme. These excerpts introduce the meaning described in each sub-theme and connect the women’s experiences to those portrayed in this poem (see Chapter 4: Study Design and Methods).

The Essence

Changing family portraits: Sudden existential absence during delirium represents the essence of the experiences shared by the women. These experiences are concerned with how the presence of a loved one as a familiar self is taken-for-granted in everyday life, and how during delirium this presence suddenly becomes absence.

During delirium the women’s loved one is a new presence, a stranger who appears suddenly and is strikingly different to their loved one. So different are they that they seem foreign, changing who the women experience as in-person, a notion described in Chapter 3: Guiding Approach. The women’s mother, father or husband is absent; replaced by a stranger. Unlike other absences and losses some women have experienced during their loved one’s dementia, this absence is unforeseen rather than anticipated, sudden rather than insidious and unpredictable rather than predictable.

For the women perceiving their loved one’s presence stems from their loved one’s familiarity, taken-for-granted understandings the women have gained through their relationships and family life over time. They assume or expect their familiar loved one will be there with them when they are together; present as always even when unwell. To expect a person in this way is described by Sartre (1943/2003) as the manner in which the women encounter and anticipate the world for them. However, the women’s mother, father or husband were no longer themselves and their situation during delirium lacked the loved one they knew so well. As explained by Sartre (1943/2003), the experience of lack is inescapably lived by the women as an absence of their loved one for them in that place and at that time. The absence the women experience comes unexpectedly, is traumatic and, together with the stranger’s presence, pervades the women’s situation. Their loved one’s assumed presence is suddenly revealed to be fragile and uncertain. Instead of being with their loved one during their delirium, the women are unexpectedly separated from them and share the world with a stranger.

16 Permission has been given by the author to reproduce 50% of the poem in this thesis
With little control over what is happening, the women live life holding on to their memories of their familiar loved one; the loved one they know, love and trust. Filled with uncertainty about their loved one’s return they wait and hope for a familiar presence once more. Waiting, the women feel isolated and yet central to their loved one’s care. At times consigned to being an onlooker, they watch their loved one’s care and feel helpless. Rather than finding reassurance and relief in the presence of health care staff in hospital and residential aged care services, the women are troubled and frustrated. They try to help their loved one but are unsure what to do to console the stranger they are with and help their loved one to return. The absence of their loved one, and the urgency and intensity of the stranger’s needs, pushes other day to day concerns from their attention. Living is a painful interplay between the loss of the familiar loved one, the present stranger and what the future holds. How much their loved one has changed and the fragility of their presence holds the women’s attention. Unnoticed by health care staff, their loved one’s absence goes unacknowledged. The women’s experience of absence and being with a stranger are theirs alone. Their family portrait, a reminder of past more familiar and predictable times, stands in painful contrast to being with a stranger during delirium.

The women’s experiences of sudden existential absence are described in greater depth in the following themes and sub themes. Together with the essence, these themes and sub themes describe the meaning of the women’s experiences as a whole (see Figure 3: Essence, Themes and Sub-themes on page 199).

**Living the Fragility of a Loved One’s Presence (Theme)**

*Living the fragility of a loved one’s presence* expresses the women’s experiences of sudden changes to their loved one’s familiarity and their absence from the women’s world. This theme comprises two sub-themes; *Facing a loved one’s existential absence* and *Living with a stranger* (see Figure 3 on p.199).

The women in the study shared life with their older loved one, a life where changing circumstances refined and redefined their *taken-for-granted* understandings of their loved one as a family member. These understandings provided a perspective through which each woman experienced her loved one as familiar and as expected. Their loved one was not just any other person in their world. They were a person whose body should reliably embody the loved one they knew, loved, trusted and expected. There should reliably be what Merleau-Ponty (1948/2004) calls a familiar “spirit that haunts the body” (p. 62). However, during delirium what the women take for granted and
expect is opposed by their loved one’s new unfamiliarity and the appearance of someone they don’t recognise; a stranger. Their loved one’s body, their corporeal presence in the world, remained but no longer embodied the spirit (Merleau-Ponty, 1948/2004) that was the women’s mother, father or husband. Their loved one’s absence threatened the women’s assumptive world, questioned how alive and embodied their loved one was, and disclosed that their loved one’s presence was fragile and uncertain.

<table>
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<tr>
<th>Essence</th>
<th>Theme</th>
<th>Sub theme</th>
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<td>Changing family portraits: Sudden existential absence during delirium</td>
<td>Living the fragility of a loved one’s presence</td>
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<td>Waiting for a loved one</td>
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**Figure 3: Essence, Themes And Sub-themes**

Experiencing a loved one’s absence is distressing for the women. They are shocked by how suddenly it happens and deeply saddened by its depth. Absence pervades their situation, getting in the way of their relationship with their unwell loved one and emphasising the seriousness of their loved one’s illness, for some foreshadowing death or serious decline.

While experiencing their loved one’s absence, the women’s attention turns to who they share the world with during delirium; a stranger who is new and unfamiliar. The new
person they meet becomes known to them through what they say and do, behaviours that are out of character and often out of control. At times what they do is bizarre, shocking and abhorrent. Their talk is fanciful and they interact with a world which is different to the women’s and not real; one where this new person sees butterflies, Nazi’s, and workmen rather than their family, their home or the hospital room. Discovering that the world is no longer shared is confusing and at times frightening for the women. The stranger’s behaviours and talk accentuate their loved one’s absence. The stranger’s presence in their loved one’s place is confronting and bewildering; they are embodied as though the spirit of their absent loved one but fall well short of who is expected. How health care staff respond to control the stranger’s behaviours is experienced as dehumanising and is distressing for the women. Experiencing the disembodiment of their loved one and the stranger’s embodiment makes the women yearn for the loved one they know, the one depicted in their family portrait and recalled from the women’s memories.

As noted previously the women’s experiences of absence, and being with a stranger during their loved one’s delirium comprises two sub-themes; Facing a loved one’s existential absence and Living with a stranger. The description begins with the sub-theme Facing a loved one’s existential absence.

**Facing a Loved One’s Existential Absence (Sub-theme)**

The operation was quite routine.

But my father somewhat troubled,

Subtly not there; with us but not of us.

(Young, 2012)

*Facing a loved one’s existential absence* expresses the women’s experiences of their loved one’s unexpected and sudden absence during delirium. The women’s mother, father, or husband is “subtly not there; with us but not of us” (Young, 2012); they are no longer in-person. Although their loved one remains familiar in body they are unfamiliar as a person. Sartre (1943/2003) describes the women’s situation as one in which a familiar person is *expected*, but experienced as *lacking* this same person. When the women are with their loved one their expectation is of their loved one’s taken-for-granted co-presence, but instead they experience absence. Coming from nowhere and catching the women unprepared, they are shocked and distressed by the rapid and inescapable truth of their loved one’s absence. Experiencing absence leaves the women feeling distanced and separated from their older loved one at a time when they
are unwell or dying. In the excerpts that follow the women share their experiences of absence during their older loved one’s delirium.

Cathy [p4] describes how, despite her mother being “really switched on” (Cathy [p4] - I1 - p1), her absence during delirium is sudden and unannounced. Her mother usually listens to the radio and keeps up to date with current events, particularly the cricket. However, during delirium she is absent and transformed; suddenly and strangely taken away. As she said:

… my daughter and I went and had lunch and we came back and the full-on madness was there, and she said “It looks like the aliens just came in and took my Nanna away.” (Cathy [p4] – I1 – p3)

Some women encounter several episodes of delirium and come to know delirium’s return. These women also describe the sudden absence of their loved one as unexpected and a shock. As Carmel [p13] describes, knowing that delirium comes and goes again doesn’t prepare her for what happens. The transition between her mother’s familiar presence and her metamorphosis into a stranger is so abrupt it is explosive; Carmel’s [p13] mother “just blew, like a volcano going off” (Carmel [p13] – I1 – p3).

In contrast with the slow and insidious erosion of a loved one’s familiarity during dementia, the women are acutely aware of their loved one’s sudden absence during delirium. The change is unlike what they have encountered before, the prior losses from dementia failing to prepare them for their loved one’s absence during delirium. Though Sally’s [p2] father has dementia she is drawn to his demeanour during delirium; to his eyes, his whereabouts, and to his look back on her. She describes looking for signs of the man she knows, loves and trusts. However, what she sees in his eyes is emptiness. She knows that he is gone and that he does not recognise her. With no recognition as a special person in his world, Sally [p2] perceives herself as a stranger to her father just as he is absent and now a stranger to her. Losing intersubjectivity Sally [p2] and her father are no longer co-present in the world. As she said;

… He’d just look at me and there was nothing in the eyes, nothing, no recognition, just dead patches in his eyes. (Sally [p2] – I2 – p3)

During delirium the women experience their loved one as disembodied, accentuating their loved one’s absence from the women’s situation. Like being “with us but not of us” (Young, 2012), their loved one’s body remains but no longer embodies their mother,
father or husband. As Sally [p2] describes, her father was not where she thought he was, revealing the unexpectedness and foreignness of disembodiment and the contradiction of his continued familiar corporeal presence. Living with her father’s absence and concurrent bodily presence is confronting and confusing. It is like living in a contradictory world.

... he was in another world. He wasn’t where I thought he was. I don’t know if he knew he was in hospital. (Sally [p2] – I1 – p33)

Like Sally [p2], Beth’s [p7] husband has dementia and she is familiar with the person he has become over time, never losing connection to him. However, when delirium sets in her husband is no longer familiar. He is “off with the pixies” (Beth [p7] – I1 – p1). The person she recalls and knows from the past is expected but gone despite his continued corporeal presence. As Beth’s [p7] said:

... he’s not with us, his mind is not with us. Physically he is. (Beth [p7] – I2 – p28).

Like Beth [p7], Ann [p1] says her husband was “off with the fairies” (Ann [p1] – I3 – p11) or was gone to the “dark side” (Ann [p1] - I3 – p16). His absence is incongruous with what she expects. It is discordant with his past familiar presence in her world and is, at times, frightening.

... And it was all dark stuff, there was nothing nice about it. I kept calling him Darth Vader, I said, “You keep going over to the dark side. You’re like damned Darth Vader in Star Wars.” (Ann [p1] - I3 – p16)

Gemma’s [p12] father had not long been admitted to hospital with a heart condition. He was now dying and had delirium. According to Gemma [p12] instead of being with her he was gone from his body, an absence that lingers until her father dies. His absence blocks their ability to share the same world before he is lost to her forever.

... you know, he was not really, he wasn’t really where he was, he was someplace else. (Gemma [p12] – I1 – p5)

Merleau-Ponty (1962; 2004) suggests that we do not usually perceive other people to be like material objects in our world. However at times, like during delirium, this changes and our perception of other people becomes as an object. In Merleau-Ponty’s (1962; 2004) view co-existence is not static and our communion can be lost when the other’s gaze is objectifying or when the other person turns away from life in a shared
world. Describing her mother as “it” and “a shell”, Cathy [p4] reveals experiencing her mother’s absence and perceiving her mother to be an object-of-the-world during delirium; as no longer human. Expressed as an inhuman gaze by Merleau-Ponty (1945/2002, p. 420), Cathy’s [p4] gaze at her mother is a look that is from the outside (Sartre, 1943/2003) and as though her mother is alien. Her inhuman gaze is distancing. It alienates and objectifies her mother, ending co-existence as subjective beings in the world and her mother’s being.

... The person I know wasn’t there at all, not at all. It’s a shell.

While their loved one is absent the women search for recognition; they want and need to be familiar and known to their loved one. They look for signs that their loved one recognises them but have no control over how they are perceived. Experiencing being recognised as a daughter or wife, some women’s existence for their loved one is confirmed, albeit intermittent and unpredictable as delirium waxes and wanes within each day. Being known by their loved one is affirming and reassuring. Being unknown is upsetting and painful. As Sally [p2] describes, not being able to predict if or when her father will know her put her on edge. Only when she arrived to visit did his look (Sartre, 1943/2003) and reactions help her to understand how it would be. Certainty about her co-presence for her father is lost. As delirium goes on, the uncertainty of being known is tiring.

... I came in and he’d look and say, “Oh, Sally.” And yet some days I felt like he didn’t like me at all. And it got a bit waring actually. (Sally [p1] – l1 – p20)

It is painful for the women to know they are no longer recognised when their older loved one needs help and support. Hearing their loved one’s loud cries for help but having no way of reassuring them is hurtful. As Carmel [p13] describes, she hears her mother screaming out loud for help from the police. Unrecognised from her mother’s other world, Carmel [p13] is no longer trusted to care and is rejected, exacerbating feelings of separation and absence. When her mother is in delirium Carmel [p13] is a stranger in her mother’s other world, as she said;

... She began screaming for help and call the police. And I was part of the problem, not part of the solution “You’re just as bad as the rest” she said. (Carmel [p13] – l1 – p3)
Unlike all the other women Ann [p1] describes knowing that her husband recognises her and that she has a place in his world; she noticed that he watched and checked on her presence often and that he knew her right from the start of his delirium.

… right from the word go he didn’t know what was going on, or anything--- he knew me then, knew me. (Ann [p1] – l1 – p2).

For Ann [p1], being known is a lifeline. It helps her to know she is not lost from her husband’s world and, though her husband is a stranger to her, she is at least known to him. She is particularly touched and reassured when, out of the blue, her husband recalls her love of sunflowers. Knowing about the sunflowers tells Ann [p1] that her husband knows who she is. It is a welcome moment of deep connection in the midst of his absences, as she said;

… I said, “Look at that photo. Isn’t that gorgeous.” And then a couple along from it are sunflowers, my flowers. [....] Years ago Al bought me a print of Van Gough “Sunflowers”. I’ve had it for years. [....] So we were coming along at lunchtime and he said, “Stop.” And I stopped and he said, “I bet you love that one. Is there a price on it?” And I said, “No, there’s not, but, but doesn’t it make you feel good when you see sunflowers?” And he said, “Yeah, it does.” And I thought to myself, yeah it does. (Ann [p1] – l2 – p33)

The following sub-theme further elucidates the women’s experiences of existential absence by describing how the women’s attention turns to being with a stranger during their loved one’s delirium.

**Living With a Stranger *(Sub-theme)*

Of blazing, crazy hues.
Of ghostly faces, horrid forms.
Evil voices murmuring evil thoughts.

(Young, 2012)

*Living with a stranger* expresses the women’s experiences of suddenly being with an unfamiliar person during delirium. Like experiencing “blazing, crazy hues” and “evil voices murmuring evil thoughts” (Young, 2012), for the women in the study the unfamiliar and changeable ways their older loved one acts and speaks is incongruous with the person they know, love and trust. As described by Merleau-Ponty (1945/2002)
the corporeal body of others is human because it is “his” or “hers”, our memory of them called into the present as taken-for-granted understandings; because it is the body of the women’s loved one and acts as the person they know. Acting in ways that are bizarre, shocking and at times abhorrent is a stark difference to the women’s familiar loved one. Through this appearance, their loved one’s body becomes an object of scrutiny; the foreignness they encounter exemplifies the otherness (see Chapter 3: Guiding Approach) of a stranger and how different the women’s loved one now is; they are “childlike”, “out of it”, “off their trolley”, “mad as a hatter” and are “not of right mind”. What they do and say is incongruous with the person the women expect, know and love; they thrash about in the bed, complain about children running up and down the ward and chase butterflies. The body of the women’s love one no longer points to the person the women know and their behaviours no longer reflect the here and now experienced by the women. Even when delirium is short lived or the women have encountered changes in their loved one from dementia, they are with a person who is unfamiliar and foreign to them. The stranger they are with is not at all like their loved one; not at all like the taken-for-granted way the women have known them before.

Being with their loved one but encountering a stranger is an unsettling and confronting experience for the women. Their relationship is not what it ought to be, making it distressing and hard for the women to be with, and relate to a stranger. They have difficulty accepting a person whose humanity is, at times, hard to recognise. Through the stranger’s behaviour and words the women encounter the stranger’s changeable and frightening other world. As Gemma [p12] describes, the way her terminally ill father acts is so different and discordant that she no longer perceives his presence. At a time when mutuality and co-presence is valued and expected, her father is foreign to her. The stranger’s presence is distancing and accentuates the pain and sadness of his absence.

… dad was a complete stranger. It was not dad anymore, it was a complete stranger. (Gemma [p12] – I2 – p2)

Sally [p2] also looks for her expected and familiar father when she visits him in hospital but finds a stranger. She describes her experience as like she “… was dealing with someone I really didn’t know” (Sally [p2] - I1-p26). In the context of her father’s advanced age and his unplanned hospitalisation, not knowing the person she is with is hard to accept and emotionally tiring.

During delirium the women’s attention is turned to how the appearance of their loved one has changed. What they say and do is odd, shocking and at times abhorrent,
manifesting the stranger's presence and accentuating their older loved one’s absence. How the stranger behaves and speaks is so incongruous with the loved one they expected. At the fore of the women’s experiences are the stranger’s loss of self-control and the loss of a shared world. What they do and say transgresses the women’s social and familial expectations, marking the person they are with as foreign and, for some, as no longer human. The behaviours the women experience are distancing and alienating, heightening the women’s experience of their loved one’s absence. It is hard for them to be present and witness what is happening. It is difficult for the women to believe that anyone, let alone their older loved one, can behave so badly. At times they are embarrassed, at others they are frightened. The stranger’s distress and their “madness” are disturbing to see and hear. The stranger’s behaviours redefine who the women are with and, like updating the family portrait, replaces their known loved one with an image of a stranger. In the excerpts that follow the women describe their experiences of sharing the world with the stranger.

As Pat [p9] describes, the stranger she was with was “out of it” (Pat [p9] – 11 – p4) and changeable. At times she thrashed around or wanted to get out of bed. At others she was closed, quiet and distant; she could have been sleeping. The stranger was doing odd things that were inhibiting a peaceful death. The unpredictable behaviour of the stranger made her mother unfathomable, adding to Pat’s [p9] distress. The differences Pat [p9] encounters make the stranger a sharp contrast to her usually “reserved” mother.

... she went from being or appeared to be heavily sedated, to be peaceful and at rest, and then she tried to move the rails and put her arm over the rails in the hospital, and she was thrashing in the bed. (Pat [p9] – 12 – p3)

Sally [p2] describes visiting her father in hospital at meal times and finding the stranger’s behaviour puzzling and disconnected from her world. There was a stark contrast between the quiet, gentle but decisive father Sally [p2] recalls and who she is with. The stranger is edgy and moved constantly. His hands and feet were everywhere. At times he would strike her. He pulled at his pyjama buttons and chased butterflies Sally [p2] could not see. With all semblance of propriety lost, what the stranger did was hideous and “wasn’t normal behaviour at all” (Sally [p2] - 11 - p19).

... he had it [delirium] and he was doing this [demonstrates chasing butterflies]. I said to the nurse, “What’s he doing?” “He’s chasing butterflies. You can’t see them, but he can” […]
And buttons and buttons --- he’d pull at his buttons. I’d say, “Stop it. Stop that”. And he’d just look at me with that expression [dead eyes]. (Sally [p2] – l1 – p14/15)

The impact of the stranger’s odd behaviour is pervasive and deep. Perceptions of a failing mind strike at the very foundation of who the women experience as being with them. Using terms they would never use to describe their older loved one, the women’s descriptions are emotionally charged. They emphasise how bizarre and out of control the stranger is to them. Cathy [p4] describes visiting her mother as being with “lunatic” (Cathy [p4] – l1 – p3). Ann [p1] says her husband is “like a mad hatter” (Ann [p1] – l2 – p25). Though Beth’s [p7] husband has dementia, during delirium he is “off his trolley” (Beth [p7] - l1 – p14). Brooke [p10] feels completely bewildered as her mother has “lost the plot” (Brooke [p10] – l1 – p12).

Experiencing what is done to control or curb the stranger’s aberrant and unacceptable behaviours is highly distressing for the women. It is also dehumanising. For some women the stranger is contained by a “straight jacket” or a “belt” as though insane or wild, stripping them of all their freedom and humanity. The use of physical restraint to control aberrant behaviours and the stranger’s attempts to escape emphasises how inappropriate and unacceptable the stranger is to health care staff and, for Sally [p2], how helpless her father has become.

… They had him in a big armchair like with a big belt around him and so he pulled at that, but he couldn’t do anything because the catch was at the back, so he couldn’t take it off, but actually in bed they have the sides up and, that was when he started pulling at his clothes and doing this butterfly thing. (Sally [p2] – l1 – p59)

Carmel [p13] describes her heart as breaking when watching her mother “throwing haymakers” (Carmel [p13] – l1 – p3) and being restrained. Her mother was acting in ways which were unspeakable and not of a “right mind” (Carmel [p13] – l2 – p16). She was screaming, climbing out of bed, running around the emergency department and wrestling with the security men trying to hold her down. The use of restraint in her care squashes all semblance of human presence. Understanding what the world and situation means to her mother, Carmel [p13] puts herself in her mother’s place. She is saddened and distressed by her mother’s loss of dignity. Losing all sense of propriety and dignity is an experience which is even more distressing for Carmel [p13] than being with her mother when, sometime later, she passed away.
... [being restrained was] Probably the most upsetting thing that I saw during the whole course of my mother’s illness. It was easier to watch her die, to be honest. That sounds a bit cruel. But to just see your mother being held down and tied up in a straight jacket and you know behaving in a way that in her right mind she never would have done, you know, I mean, she was really very abusive and being --- not behaving in the way that she would have ever presented to the world you know [....] It was just a loss of dignity and a whole --- just loss of who she was. (Carmel [p13] – I2 – p16)

For Cathy [p4], being with her mother during delirium was like being with a “lunatic” (Cathy [p4] – I1 – p3). Listening to her was difficult. She abused and berated Cathy [p4] for leaving her behind at a fictitious place. It was distressing being with her when she tried to get out of bed, displaying feats of strength and agility beyond what Cathy [p4] thought possible and reasonable for a woman of her mother’s age. It was confronting to be slapped and distressing to see her restrained by a jacket. Like cultural objects, a notion described in Chapter 3: Guiding Approach, the jacket used to restrain her mother and the padding added around her mother’s bed calls forth past experiences; Cathy’s [p4] memories of her husband’s nervous breakdown. For Cathy [p4], the jacket and padding elicit a connection between her husband and her mother, shaping her perception of what her mother has become during delirium. The dehumanising nature of restraint and padding accentuates the lunacy of her mother’s behaviour.

... for me personally, my first husband died very young, and he had what they called in those days a nervous breakdown, and he was up in the hospital and had to be put in a straight jacket. That’s a terrible sight. And I thought this was, even though it wasn’t a straight jacket as such, the putting on of this jacket, tying it at first up into a chair. But then when they got her into bed and they’re tying her into bed it was just awful. [....] It seems to dehumanise them. You know. Because I said, “Is it really necessary?” “Well, we don’t want to hurt her.” Well fair enough. You can see that. And after that as well they had to put padding over the rails because she kept trying to get out and putting her feet and legs through the rail and trying to get out of the bed. And I kept thinking, gosh, it’s like a padded cell. (Cathy [p4] – I1 – p14)
Adding to the women’s experiences of their loved one as no longer a person like them, and no longer co-present, the women encounter talk which makes no sense. What the stranger says is nonsense; talk which is fanciful, troubling, and, for some, disagreeable. It points to the presence of multiple worlds and the un-realness and madness of the stranger’s world. Language, as a past shared cultural object (Merleau-Ponty, 1945/2002, p. 413), no longer allows the constitution of shared meaning. Their perspectives can no longer merge into each other to become shared meanings. The stranger’s thoughts are theirs only and what they say and see is not real to the women. As Janine [p8] describes, her mother talked about the Nazis during her hospital stay. Siblings Sharon [p5] and May [p6] describe their mother as talking endlessly about people that were invisible to them. What she said was amusingly out of place but became irritating and alienating as it persisted.

... when she started on you know, “I don’t know why the nurses don’t stop these children racing up and down the thing on the skateboards”, and we’re thinking right --- “They’re all in there throwing marbles. They should be stopping them”. And she went on and on about it. (May [p6] – I1 – p16)

Cathy [p4] describes experiencing her mother’s different world; a world that was all in her mother’s head. Her behaviours are out of tune with Cathy’s [p4] situation and it was very distressing to watch the stranger’s emotions swing unpredictably. How the stranger interacts with Cathy’s [p4] world makes her mother stand out as different. Madness is never far from Cathy’s [p4] thoughts about the stranger she is with.

... totally off with the pixies. It was as if she had her own video running in her head that we couldn’t see, but she was interacting with this mental image and you know, sometimes she’d be laughing and other times she’d be angry. And it’s hideous to watch. It’s really terrible. (Cathy [p4] - I1 - p1)

The stranger Gemma [p12] describes was in a fictitious world which at times included people who wanted to do harm or animals behaving oddly.

... animals, or workman working and animals flying around and then even people that were, well he said, “I just hope that if they get me they slit my throat quickly, because I just don’t want to be tortured. I want them to slit my throat, so I die quickly” [....]
he just, dreamt up things, or things happened in his head, that weren’t really happening. (Gemma [p12] – I1 – p8)

How the stranger acts can be foolish. At times what Gemma’s [p12] father says is embarrassing, as when he chimed over and over “Dr Boo did a poo” for all at the hospital to hear. The distress Gemma [p12] hears in his voice is saddening. Unforgivably, the stranger takes the place of her father and erodes his dignity until his death.

Some of the women are surprised and affronted by the use of language which has never been uttered by their loved one; both colourful and rude. Carmel [p13] describes hearing language which is out of character for her mother and way beyond what Carmel [p13] felt was socially acceptable or what a sane person would say.

... the language, whew, you know, things that she said that I didn’t think she even knew those words. She was really --- my father used to joke that when he met her she wouldn’t say “shit for a shilling”. That was a joke that he used to --- but I tell you what she certainly made up for it that day. (Carmel [p13] – I1 – p3)

The women’s experience of sudden existential absence and a stranger’s presence is further elucidated through the second theme; Living life holding on. This second theme discloses what it is like for the women to wait for delirium to pass and for their mother father or husband to once more have a presence.

Living Life Holding On (Theme)

Living life holding on communicates the women’s experiences of waiting for their loved one’s uncertain return and reveals how they experience their relationship with health care staff. It comprises five sub themes; Waiting for a loved one, In the dark, On the fringe but centre stage, On thin ice and Keeping secrets (see Figure 3 on p.199).

With little control over what is happening during delirium, the women live life holding on to their memories of their loved one and hope that their familiar loved one will return; that they will once more be with their mother, father or husband. They turn their attention to the stranger and search for signs that their loved one is back. With few explanations for their loved one’s absence and little certainty about their return, their waiting is hard to bear. It is like living in the dark.
When relating with health care staff the women are prevented from sharing what they know about their loved one’s health and, for some, how prior delirium has been. Often dismissed and at times belittled, the women are relegated to the side line and to looking on as care is decided and delivered. They feel responsible for their loved one but isolated and helplessness to change what health care staff do. Rather than finding reassurance and relief through the presence of health care staff, the women are frustrated and at times troubled by what is happening. Despite the stranger’s madness, the women visit and attempt to console and care for the stranger. The intensity of the stranger’s “madness” pushes the women’s other day to day concerns into the background and heightens their need for the stranger’s presence to end. When with the stranger the women are unsure what to do and feel helpless to control what the stranger says and how they act. The women’s experiences of their loved one’s absence and the stranger’s presence are passed over by health care staff.

Some women experience their loved one’s return after recovery from delirium but go on to encounter delirium again. For these women everyday life has the ever-present possibility of delirium, of suddenly losing their loved one and facing a stranger again. Predictability and certainty about their loved one’s future presence is lost, adding to the women’s experiences of the fragility of their co-presence in the world and the changeability of their loved one. The possibility of re-experiencing their loved one’s absence keeps these women watchful and on guard for the stranger’s return. When delirium is gone the women treasure their loved one’s presence. Never sure when their loved one will change, their situation is like living on thin ice. When their loved one is in-person the women keep the stranger’s presence a secret. Acting like a shield this secret protects their loved one from knowledge of the stranger and knowing what they became. These secrets reveal the close ties between family members. For some women the secrets are a burden and change the way they relate to their older loved one after delirium passes.

In the following five sub-themes the women’s experiences of Living life holding on during their loved one’s delirium are further elucidated. The description commences with the sub-theme Waiting for a loved one.

**Waiting for a Loved One** *(Sub-theme)*

But he looks quiet now.
The earlier rage all whimpered away.

(Young, 2012)
Waiting for a loved one expresses the women’s experiences of enduring the stranger’s presence while waiting for their loved one to return, revealing a temporal dimension to their situation. As in Young’s (2012) observation, “he looks quiet now. The earlier rage all whimpered away” (Young, 2012), the women turn to their loved one and search for signs that the stranger has gone. While living with their loved one’s absence, they look forward to again sharing the world with their mother, father or husband. They are eager for their loved one’s presence; a presence that matches past taken-for-granted ways of knowing their loved one and constitute familiarity. They hope that the stranger is temporary, that their loved one will return and that their experience will once more be the same as they recall from their family portrait. With no certainty about when or if their loved one will return, and little control over what is happening, waiting can be arduous.

In the excerpts that follow the women share their experiences of being drawn to their loved one’s appearance and waiting for their loved one to once again be in-person and co-present. As they wait, their loved one’s absence and presence waxes and wanes, making it difficult for them to know who they are with at any one time and when their loved one has returned for good. As Janine [p8] describes, her mother had dementia but came and went when she had delirium. Janine [p8] just didn’t know which it would be or when it would end.

... something kept breaking inside her head, so there was times when she was quite normal [...] and then suddenly--- yeah, it was like something just went blank. (Janine [p8] – I1 – p10)

The women’s experiences are speckled with unpredictable short presences of their loved one in-person, fuelling the hope that they can return. The women look to their loved one’s corporeal presence and search for the person they love, know and trust. As May [p6] describes, she watches her mother’s physical reactions to see if she is “the same again” (May [p6] – I1 – p19). Cathy [p4] describes listening for conversations that are no longer filled with nonsense from the video running in her mother’s head. Carmel [p13] looks into her mother’s eyes. As she says;

... you could look into her eyes and when they were clear you knew that everything was alright. But sometimes she’d get a real glazed, starey, watery, funny look in her eyes and you just sort of knew she was somewhere else. (Carmel [p13] – I1 – p10)
Even sensing mum briefly was a relief for Carmel [p13] from the pain of her mother’s absence. For all the women fleeting presence rekindles the women’s connection to their loved one and nurtures the possibility of their future and more permanent return. When, once again, their loved one becomes absent, the women’s hopes turn to disappointment. Being with a person who shifts randomly from in-person to in-stranger is an experience filled with uncertainty; it is like living on tenterhooks. As Ann [p1] describes, she could never be sure who she would encounter right from the beginning of her husband’s illness. Moments when he is there were few and they are brief. He changed when Ann [p1] least expected and would no longer be like the man she knew. The fluctuating nature of her husband’s presence is difficult and strange to experience. She is watchful and attentive to who is there and protective of herself; “I’m on my guard a lot with him still” (Ann [p1] – I3 – p8). Ann’s [p1] visits are filled with unpredictability and caution.

... because I don’t know what’s going to happen when I get here you know. I mean some days I’ve come in and he’s not too bad and then other days he’s off with the fairies all day you know. So, you can’t, I haven’t been able to predict it [...] and when I was coming in today I was thinking to myself, well I wonder if we’re going to have two steps forward, or two steps back today you know. (Ann [p1] – I1 – p22)

Good visits for Ann [p1] are when her husband “shone through” (Ann [p1] – I3 – p12). Though not back for good, Ann [p1] can relate to the man she married and who fathered their children for a while. Noticing times when her husband is back fuels hope and provides reassurance that his absence may not be forever.

... I always ask him what he’d like for lunch tomorrow. He said, “I’d love a hot sausage sanger [sandwich].” And I said, “Would you really. Okay. I’ll cook you some sausages, we’ll do you a hot sausage sanger.” So he said, “Righto.” When we came in today, he’s all the time watching for me you know, and as I come, from the corner, he said to me, “You got the sausages?” So I thought that’s Al. Al’s back, you know. (Ann [p1] – I2 – p31)

Uncertainty about absence and presence pervades Carmel’s [p13] experience and, like Ann [p1], she feels uneasy and wary of the stranger’s presence. She braces for the stranger’s madness and waits, all the time checking for her mother. Though she is
used to how her mother is with dementia she is uncertain about when the stranger will leave and how bad things will be while the stranger remains.

... I became sort of wary, you know, wondering what was going to happen, because you never quite knew which way she would jump, you know. Sometimes she would just, you know, when that happened, she might just get really weary [...] But other times she’d start to wind up. (Carmel [p13] – I2 – p20)

Gemma [p12] also describes never knowing what her father will be like. She visited her father in hospital every day and notices that each day starts off differently. The experience of waiting for her father’s complete return is like a “roller coaster” (Gemma [p12] – I1 – p10). She has no control over who she was with and her experience is full of emotional highs and lows. She has no idea when the ride will stop, and when it does who will be there.

For Beth [p7] the distress of waiting for her husband’s presence is eased by the predictability in his fluctuating absence and presence. As Beth [p7] describes, though her husband’s presence was brief during delirium, being able to follow how he would come and go gave her confidence that he would return.

... every now and again you would get patches of clarity [...] and then it would sort of fade away as the drugs wore off and then it would come back again. (Beth [p7] – I1 – p16)

How long all the women have to wait and suffer the pain of their loved one’s absence is unknown and beyond the women’s control. Revealing a temporal dimension to their situation, the women wait and see what the future brings. For some women their loved one’s presence returns completely and as quickly as it went. The stranger now gone, these women have an end to their waiting and the distress of absence. As Lyn [p3] describes, her mother’s hallucinations passed quickly during their visit to the emergency department and she was back to her old familiar self. Although shocking and distressing, Lyn’s [p3] loss and waiting is brief. Siblings Iris [p14] and Betty [p11] describe their mother as fine again, as soon as her infection is dealt with. Their mother’s returned presence was “sort of instantaneous [...] it was chalk and cheese” (Betty [p11] - I2 - p14) once her antibiotics worked. Carmel’s [p13] mother returns to how she was with her dementia soon after her antibiotic drip is commenced and is “you know… back to her old self again” (Carmel [p13] – I3 – p32). Absence for these women is sudden but is experienced as temporary. Their expected loved one is returned to
them once more and their situation is no longer characterised by lack (Sartre, 1943/2003). As Betty [p11] describes, she is relieved each time her mother comes back and is grateful.

...You just think, “oh, that’s old mum again”. It’s not this sort of confused, almost like she was in some sort of a daze, walking around half asleep, and then all of a sudden she’s awake. (Betty [p11] - I2 - p14)

Even when dementia is present the return of the women’s loved one is clear and a relief. As Beth [p7] describes, her husband comes back to his familiar self when the treatment for his pneumonia works. Unlike Beth’s [p7] experience during his dementia, the changes from delirium are temporary and can be waited out.

... he’d had pneumonia and of course the infection screwed him up. [...] it was really quite a nasty. (Beth [p7] – I1 – p1)

For other women their loved one’s absence drags on, lingering day in and day out and well beyond the acute illness that set their loved one on this path. Like living a life in limbo, the stranger these women share the world with never fully leaves and their loved one never fully returns. Though they experience moments of presence their loved one’s absence has no foreseeable or definitive end. In limbo, the women confront a view of the world that is at odds with the future that should have been. As Ann [p1] describes, she is caught in “a wait-and-see situation” (Ann p1 – I2 – p23). Uncertain when her husband will fully return but told that he will, Ann’s [p1] time is filled with uncertainty about her husband’s future presence and their life together. She fears what may lie ahead. Waiting is a labour of her love and she is worn out from waiting; “It’s a long haul. Oh my God, it’s a long haul” (Ann p1 – I1 – p39). When it is time for them to go home her husband is not back to being the man she knows. His absence lingers and pervades their world like a dark cloud.

... apart from a few--- a few lucid moments he’s been troubled and confused and hallucinating the whole time. The whole time, yeah.[sigh] (Ann [p1] – I1 – p2)

Other women also experience lingering absences that are relentless and inescapable. These women’s losses are weighty and their sorrow is deep. A new and altered view of the world is realised. As siblings Sharon [p5] and May [p6] describe, they thought their mother would recover after her surgery but she never returned. They thought that she was strong and trusted she would return to being the mother they knew and loved. Now
at home, their mother “just wasn't her anymore.” (Sharon [p5] – I1 – p60). Having no opportunity to have their mother with them, Sharon [p5] and May’s [p6] loss permeates their caring. At home without their mother the sorrow of their loss is held back.

...Because you’re in this go, go, go mode all the time. It’s a detachment from life. When you’re a carer you are detached from life. You’re in this bubble. (May [p6] – I2 – p23).

Experiencing an absence that lingers is heart-breaking for the women when their loved one is dying. As Gemma [p12] describes, she waits and hopes for the stranger to leave and for a chance to talk to her father before he passes away. Premature, untimely and ever present, her father’s absence “got in the road” (Gemma [p12] – I2 – p18) and made it difficult to talk about matters important to her. It creates a world without goodbyes.

...And by the time you got to that stage dad was, I don’t think he comprehended it, you know, what you wanted to say, he was past that. (Gemma [p12] – I2 – p2)

Like Gemma [p12], the sudden absence of Pat’s [p9] terminally ill mother stops them from talking. She is intensely sad and disappointed that she has lost the chance to say goodbye. Like Gemma [p12], Pat [p9] never again experiences her mother’s presence and the last portrait she has is that of the stranger.

...she appeared to be towards the end of her life, which was a shock to me, considering that I’d only spoken to her a few days before and she was able to have a conversation. But I couldn’t really have a conversation with her. (Pat [p9] – I – p1)

Waiting for their loved one is made more difficult for the women by not having an explanation for their loved one’s absence or the stranger they share the world with, an aspect of their experience described through the next sub-theme; In the dark.

In the Dark (Sub-theme)

“Dehydration, infection and constipation.”
So we are told.
An oddly innocent litany,
To inflict so grave an ill.

(Young, 2012)
In the dark communicates what it is like for the women to have little explanation for their loved one’s absence or the stranger they share the world with. Like being told “An oddly innocent litany, To inflict so grave an ill” (Young, 2012), the women seek explanations that speak to their loved one’s absence and the stranger’s presence. Turning to health care staff the women seek explanations that will help them come to grips with their situation and to know how long they will need to endure the stranger’s presence. Lived is the inadequacy of medical categories in explaining their experiences and the different world of health care staff. Not understanding their experience adds to the uncertainty which permeates the women’s experiences; it is like being left in the dark. It is harder for them to maintain hope for their loved one’s safe return and know what to do when they don’t understand. With few answers the women struggle to make sense of what has happened and to know what the future will be.

In the excerpts that follow the women share their experiences of searching for explanations but being left in the dark. In their search they encounter the taken-for-granted world of health care staff, a world where infection or age is enough to understand the stranger’s presence. What is new and distressing for the women, is familiar and less remarkable for health care staff, revealing differences in their perspectives, concerns and lived worlds. As Lyn [p3] describes, she didn’t have any explanation for her mother’s absence, the stranger’s presence or the mad behaviours she experienced during her mother’s bladder infection. She had worked out and grown comfortable with what it was like to live with her mother and her dementia but there was nothing that explained why her mother was absent during delirium. “Bladder infection” just left her wondering.

... I didn’t have any explanation for it. I mean, I was used to her being--- I was used her being, what’s the word, demented [demented]. (Lyn [p3] – 11 – p13/14)

Gemma [p12] describes knowing her father was dying but having unanswered questions about the stranger’s presence. His terminal care had come suddenly and, though she knew what dying meant, his absence from her world didn’t fit with what she expected. She perceives the staff’s discomfort in talking to her about what is happening but is frustrated and disappointed when they avoid explaining why her father is lost to her. Left without answers Gemma [p12] looks for her own explanation and wonders if the hospital renovations or a failing body are responsible for the stranger’s presence.

... I found that they--- I don’t know I just think that they could have been better, like they could have told us. It seems like they
don’t like to tell you, but you want to know, you want to be told, but they sort of hold back because they think, I guess they’re going to upset you or worry you, or that they might say something that’s not quite right. (Gemma [p12] – I1 – p15)

Like Gemma [p12], Pat [p9] describes looking for answers. She wants to understand why her mother has changed so much and so quickly. Although her mother’s condition has been called delirium it has little meaning. Pat [p9] searches for other answers that shed light on her mother’s absence and the stranger. She just can’t fathom what has happened.

... because my question always was, I left her ten days before where I was able to have a conversation, but she’d gone into this delirium and what had caused this? What had caused it? And I didn’t know whether it was the actual lack of oxygen, or out of familiar surroundings. (Pat [p9] – I1 – p2).

As Cathy [p4] describes, she accepted “infection” as the medical category for her mother’s illness but it didn’t explain the stranger’s presence; it was like being kept in the dark. For Cathy [p4] her mother’s absence is at the centre of her experience and hopes for the future. For health care staff her mother has a treatable infection, highlighting their different perspectives on the situation.

... It was just, “Oh, your mothers got a bladder infection, but we’re treating it”. You know. And, well the first time it happened I had no idea that a bladder infection--- they say constipation in the elderly is the same. And I had no idea that that was something that happened. [...] we didn’t really get a lot of explanation, well, I didn’t feel there was a lot of explanation, other than, “Yes, it’s something that happens in the elderly. It affects their mind and we treat it with antibiotics.” That’s basically all we were told. (Cathy [p4] – I1 – p5)

Understanding her husband’s absence was also important to Ann [p1]. Like other women Ann [p1] describes searching for answers but is frustrated when health care staff are unable to explain.

... they were doing all of those tests on him and so forth and everything was coming back negative, negative and the doctor on the desk down there, he just said, “I’ve tried everything. I’ve
tried everything. There’s no explanation for his mental attitude”.

(Ann p1 – l2 – p23)

Having no answers eats at Ann’s [p1] hopes for her husband’s return and makes waiting harder. She is fearful that the stranger will stay and worries about the future. Unlike other women, some relief and reassurance comes for Ann [p1] when later a nurse offers delirium as an explanation. Knowing there was at least a name for his absence helps Ann [p1] to cope with the strangeness of her situation and sustain hope for her husband’s return. Though it didn’t explain his absence it was something she could hang onto; there was at least a name for it.

... that there was a reason he was like he was, it was delirium, you know. There was a name for it, a name for it. (Ann [p1] – l3 – p31).

While waiting for their older loved one the women experience being on the fringe in their relationship with health care staff and yet centre stage in caring for their love one, an aspect of their experience described in the following sub-theme.

**On the Fringe but Centre Stage (Sub-theme)**

This is routine stuff for us!
“We badge you, stamp and wrap you.
Then cut you, mend and dispatch you.”
All proclaimed with a smile,
But the eyes are distant, detached.
Another day; another hip.

(Young, 2012)

*On the fringe but centre stage* expresses how the women experience contradiction in their role during their loved one’s delirium. The women enter their situation with an expectation that they will be valued, that health care staff will listen, they will have a respectful reciprocal relationship with them and that staff will know how to care for their loved one. However, like Young’s (2012) observation that “the eyes are distant, detached. Another day; another hip”, the women in the study experience health care staff as distant and disengaged, having concerns that are different to their own. Through their relationship with health care staff the women experience being unknowing, dismissed and at times belittled. They are isolated, consigned to being an on-looker as staff make decisions and deliver treatments. Despite this they persist and
care for their loved one when and how they can. The urgency and intensity of their stranger's needs pushes the women's other day to day concerns into the background. Being with their loved one and caring creates a completely new routine. Seeing health care staff have difficulty managing how the stranger acts erodes their trust. They watch on and, like the staff, feel helpless to console the stranger they are with. Rather than finding reassurance and relief the women are troubled and frustrated. They feel caught and responsible for helping to care but unsure what to do. Caring is like starting from scratch; all trial and error. Their loved one's absence goes unnoticed by health care staff. Though their love, conscience and family roles call on the women to be with their loved one, they find it confronting and hard to be present and encounter the stranger.

In the excerpts that follow the women share their experiences of being concurrently on the fringe and centre stage during their older loved one’s care. Revealed by these experiences is how alone and marginalised the women are in their relationship with health care staff and yet how important they are to their loved one's care. Central to Beth's experience is being pushed to the fringe by health care staff and the helplessness she feels. As Beth describes, she becomes annoyed and frustrated when she is not listened to and is disregarded. Though she is a carer her understanding of her husband’s needs is not valued and her sense of importance is diminished. Her trust in her husband’s carers and their care is called into question, then eroded. She says;

... They're not listening to me, not listening to me at all. And I was getting a bit cross because I kept saying the same thing over and over again. They kept talking to him, and he was off with the pixies. Had absolutely no idea where he was. He didn't know what was happening. And they're saying to him, “Speak to me, Speak to me.” And I'm thinking to myself, he's not going to speak to you. (Beth [p7] – I1 – p1)

Very aware of her husband’s uncharacteristic behaviour, Beth [p7] spends long days by his side to keep him safe. She feels compelled to stay to make up for the staff’s focus on technical care.

... The nurses only came to take his temperature on him, however often they had to take his temperature. [...] Short of that they didn't see him other than to check on the cannula, because he had a cannula of some sort. (Beth [p7] – I1 – p14)
Though helping with her husband’s care, Beth [p7] thinks her presence is annoying and intrusive for staff. Despite not feeling welcome, Beth [p7] wishes she could have been more forthright and stayed longer. Finding her husband worse each time she returned is painful for Beth [p7] and accentuates how alone she is in watching over her husband. Not trusting the nurses’ care made leaving her husband difficult.

… The nursing staff said “You’ve got to go home. They’ve got to have their rest time. You’ve got to go home”. And I could have I suppose been quite forthright and said “Well, I’m bloody well not going home because you’re not going to sit here with him and make sure he’s alright.” [...] But I went home and each time I did I came back and he was in a state of further confusion.

(Beth [p7] – l1 – p13)

Like Beth [p7], Carmel [p13] knows her loved one well and understands what she needs. Carmel [p13] has endured many episodes of delirium and knows how delirium evolves and how her mother transforms into a stranger.

... I sort of recognised what was happening, probably more than the staff did actually, because I knew her a lot better. (Carmel [p13] – l1 – p7)


... when I tried to speak to them to tell them what was happening with her I sort of got a pat on the head and said “It’ll be alright dear. We’ll cope with it.” But I knew that it wouldn’t be alright, but nobody would listen. And because you’re just the relative you don’t really have any status [...] And they’re not really taking it on board and they’re not taking you seriously because you’re not a health professional. What would you know? (Carmel [p13] – l1 – p7)

When looking on Carmel [p13] notices the staff panic and her mother’s care move from reasonable to desperate. Surrounded by hospital staff who seem unsure what to do,
her mother’s care escalates, becomes physical, chaotic and way too late. Left to look on, Carmel’s [p13] is alone, distressed and no longer able to help.

... Well they were sort of a bit panic struck, you know, she was swinging punches at people. No one could contain her [....] They ended up calling the security staff who were on and two burley young men came in and sort of took an arm each and physically man-handled her onto the bed. The nurses sort of threw themselves across her body to hold her down on the bed. And she was screaming and struggling. They gave her first injection of Valium and hoped that that would work, but it didn’t. So, the second one slowed her down a little bit. That’s when they put the straight jacket on her and restrained her with that. But it was all hands on deck. People came from everywhere to sort of--- yeah, it was quite an upset. (Carmel [p13] – 12 – p15)

Previously disregarded and marginalised, Carmel [p13] is surprised and disgruntled when she is called upon to care for her mother. She perceives the staff are frustrated by the stranger’s behaviour and expect that she will know what to do, as though knowing her mother will help her control someone who is a stranger. Revealed in the staff’s actions are assumptions about Carmel’s [p13] knowledge of the stranger, and her willingness and ability to care for her mother in a hospital ward.

... And then they were saying to me, “Can you keep her in bed?”
“No. I couldn’t”. They wanted my help to control the screaming and the raging. (Carmel [p13] – 12 – p30)

Cathy [p4] perceives residential aged care staff expect her to know what to do when her mother is a stranger. Called early one morning by residential aged care staff, Cathy [p4] is drawn into her mother’s care during delirium and is centre stage. Once there Cathy [p4] describes feeling abandoned and helpless but responsible; she is left alone to care for her mother. Revealed are staff assumptions about Cathy’s [p4] familiarity with the stranger and her ability to manage the stranger’s behaviour. Unacknowledged by the staff is Cathy’s [p4] perception of her mother’s absence and the foreignness of the stranger.

.... Six o’clock they rang me, but I didn’t get there till about 8, and there she was at the dining room table all hunched over and trying to pull the table cloth off and doing all sorts of
strange things. And then they took her back to the room and I stayed with her at the room because they said they’d rung the doctor and nobody came and I eventually had enough of that so I eventually rang the after-hours service myself. […] We had to push the bed up against the wall to stop her from falling out, or getting out. (Cathy [p4] – l1 – p1)

For some women being disregarded draws out their time with the stranger, adding to their frustration and distress. Enduring repeat encounters with her mother’s delirium Cathy [p4] just knows what works when her mother gets to hospital; what will stave off the stranger’s presence and reduce the odd behaviours. Though she knows what has worked before she is disregarded by hospital staff and pushed to the fringe. The stranger’s presence goes on unabated and she has little influence over what care is given.

... So they started giving her the medication orally and every new staff member I saw I said, “Look she doesn’t respond well to oral. She needs intravenous.” “Oh, no, these new drugs”. Because you’re a lay person they think you don’t know, but I’ve had so much history with mum, with this sort of thing, so her delirium went on for days. (Cathy [p4] – l1 – p1)

Though Cathy [p4] doesn’t really know how to care for the stranger she is compelled to stay and try. However, stepping in to care takes a toll. Cathy [p4] becomes overwhelmed and exhausted. She is saddened that health care staff resort to physical restraint when she has to give up. Caring for the stranger seems hopeless.

... mum kept trying to get out of bed, my son and I were exhausted from trying to hold her back in the bed to give this nurse who was looking after all these other aged people who were in this room a break, because she just wasn’t--- she’s one person and there were four aged people in bed that were needing her services. We tried as much as we could until it just got beyond us and then they put the jacket on her and strapped her in. That didn’t stop her trying to get out. (Cathy [p4] – l2 – p11)
Ann [p1] stayed at the hospital with her husband and describes watching health care staff deliver care. She sees confusion in their eyes and perceives their frustration. She notices they can't cope with his bizarre behaviours.

... I just got that impression right from the word go and the fact that all this hallucinating and whatever you want to call it, no one was able to cope with that. They had him in a room on his own at the nurses' bay you know. (Ann [p1] – l2 – p21)

During her husband’s delirium Ann [p1] is responsible for keeping him calm and settled. Health care staff can’t cope when the stranger is present. Full of sadness and responsible for the stranger, Ann [p1] is alone caring.

... But when I’m there, I’m there from say 11, 11.30 of a morning until 7 ish at night, when I’m there I’m able to keep him under control, I’m able to keep him--- and they don’t really have to do much for him, apart from giving him his drips and all that you know. (Ann [p1] – l1 – p32)

Labelling Ann’s [p1] husband a psychiatric patient, the nurses signal their rejection of the stranger and displeasure in caring for him. The nurse’s comments intensify how alone Ann [p1] is while waiting for her husband’s presence, and how centre stage her presence and care is.

... you know “Well, we are an orthopaedic ward. We’re not a psychiatric ward.” You know that sort of thing. That was said quite blankly in front of him, one of the little nurses said that. (Ann [p1] – l2 – p20)

Caring for her husband in hospital is like starting from scratch for Ann [p1]. She has no prior experience and has to see how it goes. When with her husband she brushes his forehead and back, and scratches his head. She pulls down the blinds so the shadows can’t be transformed by his mad thoughts. She holds his hand and holds his body when it breaks loose and acts in mad ways. Confirming what she sees in her world Ann [p1] pushes her husband’s unreal world away.

... And he’d be throwing his hands around and I’d be grabbing that hand, putting it down and hold it and he’d open his eyes and I’d say, “There’s no one there. There’s only you and me.” (Ann [p1] – l1 – p20)
While caring Ann [p1] doubts herself and is uncertain if her care is what should be done for Al. Surrounded by health care staff but unable to ask Ann [p1] is centre stage and alone working out what to do.

... I wanted to say to the nurse, “Look, when he’s goes off like this, should I join him, or should I just keep bringing him back? What’s the thing to do? What’s the, not the correct thing, the sensible thing to do here? To go with him in his truck driving up the highway, or the boat, or whatever it is. [...] What’s the sensible thing to do?” I’m thinking to myself, you know. Should I go to this boat with him? (Ann [p1] – I2 – p26)

There is little guidance in how to care and, at times, the madness worsens. The stranger’s behaviour is out of control and she is frightened. Confronted with escalating bizarre behaviour Ann [p1] works instinctively and scolds Al as though a child.

... I’ve sort of gone along with the ride, but some of the times there when he got umm quite umm--- he got quite aggressive a couple of times, a few times there, and sort of yelling out and things like that. I’d bring him back and say, “No! That’s not acceptable behaviour you. You know better than that.” (Ann [p1] – I2 – p10)

As home based carers Sharon [p5] and May [p6] hoped their mother’s admission for surgery would give them a couple of days without care responsibilities. However, summoned by recovery and ward nurses to help with their mother’s care, responsibility shifts back to them. Although the nurses continued to tend to technical aspects of their mother’s care, Sharon [p5] and May [p6] became responsible for calming her down, keeping her in bed and controlling her behaviours. They noticed the staff’s annoyance at their mother’s behaviours and frustration at how much time her care was taking. The staff seem to assume that this is how their mother was when not in delirium. Surrounded by health care staff with no time for patients who are difficult, Sharon [p5] and May [p6] are centre stage in their mother’s hospital care.

...That was when she had the hallucinations. The staff really were not even interested in anything were they, because as far as they were concerned she was just being a difficult deaf hundred year old lady. They had no idea that she was--- I don’t even think that they were aware of what it was or anything else,
she was just being a difficult hundred year old. And they didn’t need that when they had others to care for. (May [p6] – l2 – p91)

Though their mother was very old and was to stay in hospital after her skin graft, plans suddenly change when their mother is “difficult” for staff to care for. “Evicted” (May [p6] – l2 – p132) from hospital Sharon [p5] and May [p6] are rejected, annoyed and alone. The responsibility for their mother’s care is shifted into their family home. There is no doubt they are centre stage at home as well.

... but we felt like we were being evicted. Sharon and I thought that she was being too difficult, it was taking too much resources, too much of their time, that needed to be divided amongst the other people, so send her home. (May [p6] – l2 – p132)

While all the women wait for their loved one and experience being on the fringe in their relationship with health care staff and yet centre stage in caring for their love one, some of the women experience their loved one’s returned presence only to find delirium reoccurs, an aspect of their experience described in the following sub-theme.

**On Thin Ice (Sub-theme)**

But that was yesterday,  
And those several days before.  
A perfectly, perfect man, utterly undone.  

(Young, 2012)

*On thin ice* expresses how some women experience the ever-present possibility their loved one will transform suddenly and be absent once more. Like “But that was yesterday, And those several days before. A perfectly, perfect man, utterly undone.” (Young, 2012), some women in the study experience their loved one’s returned presence, only to find they are lost again in future delirium. Predictability and certainty about their loved one’s future presence is lost, adding to the women’s experiences of the fragility of their *co-presence* and the changeability of their loved one. They live the ever-present possibility of sudden absence and the threat of the stranger’s presence. The possibility of absence engenders apprehension. When their loved one is well it keeps these women watchful and on guard for the stranger’s return. Like living *on thin ice* these women are never sure when their world will suddenly crack, delirium will
appear, and their loved one will suddenly leave. They are wary, fearing their loved one will become delirious again and no longer familiar. In the excerpts that follow the women share their experiences of living on thin ice.

Sharing her experience, Cathy [p4] describes never knowing just when her mother will have another infection and she will become absent again. Not knowing is hard to bear. She is apprehensive, feeling like she is living “on pins and needles waiting” (Cathy [p4] – I1 – p2). Like other women who experience recurrent episodes of delirium, Cathy’s [p4] attention turns to her mother’s corporeal presence to help her navigate her uncertain world. She recognises tell-tale signs that signal the stranger’s presence and warn that she has little time to react. The stranger’s presence is so horrid that Cathy [p4] works to avoid or minimise the stranger’s presence. Seeking help early helps Cathy [p4] to exert some control over her mother’s transformation and her situation.

… And you’re watching for things and listening for things. My son and I were visiting there one day and she said something, I can’t remember what it was now, but it was a bit off-the-wall and it didn’t fit to what we were talking about at the time, and she was faltering in her speech and that, and we sort of looked at each other and thought, oh no here we go. I went down quickly to the staff and said “I think she needs another test to see what it was”. And if they get it at that stage the oral medication works, but if it’s when she’s full on into the madness the oral just doesn’t seem to work (Cathy [p4] – I1 – p4).

Like Cathy [p4], siblings Betty [p12] and Iris [p16] describe the ever-present possibility of the stranger. Over time they also come to know what to look for, and to seek help to stop their mother’s transformation. They connect their mother’s absence with the differences they experience when their mother has urinary tract infections. Knowing their mother’s pattern and acting early provides a sense of control over, and protection from, the stranger’s presence. It helps them to live with how unpredictability their situation changes; how the thin ice cracks with only a moment’s notice.

… we realised that it was a urinary tract infection and we were just more aware that next time she starts to act a bit odd, what to look for, and we’d say, “I think we need to take a sample”. (Betty [p12] –I1 – p8)
Sharing her experience Lyn [p3] describes how she couldn’t work out her mother’s absence the first time but when it happened again she was forewarned and knew what to do. Though her mother has dementia, knowing and looking for a pattern then acting quickly helps to keep her mother present.

... she was sitting up in bed and we’d been there all these hours and they’re trying to work out what was wrong. [....] But this made her sick, you know, she was lying in the bed, she was weak, they came to take her, because I didn’t know what it was and I rang the ambulance and they had to sort of help her on the trolley and trolley her out. But after that I knew what it was and I got onto it straight away. (Lyn [p3] – l1 – p12)

Some women live with the uncertainty of delirium’s return and some experience keeping how their loved one changes during delirium a secret, an aspect of their experience described in the following sub-theme.

**Keeping Secrets** *(Sub-theme)*

A ravaged body, emptied and spent.
A living husk that somewhat recalls,
A happier memory: a father.

(Young, 2012)

*Keeping secrets* depicts some women’s experiences of concealing the stranger from their loved one. Though all women experience the stranger, some find the stranger is not recalled by their loved one after delirium passes. They realise they hold privileged knowledge of their loved one and the past, a time when their loved one was a stranger and full of *otherness*. Like maintaining “a happier memory: a father” (Young, 2012), keeping the stranger secret is like shielding their loved one from the likely distress of knowing they were not themselves; that their behaviour was out of control and at times unspeakable. Keeping secrets reveals the close ties between family members but they are also a burden. For some women they change the way they relate to their loved one after delirium passes. In the excerpts that follow some women share their experiences of concealing the stranger from their loved one.

As Carmel [p13] describes, after the delirium passed she was relieved that her mother couldn’t recall her bizarre behaviour and being restrained. By hiding the past she shields her mother from knowing about herself and further distress; from knowing what
she was like from the outside, a perspective described in Chapter 3: Guiding Approach. Carmel [p13] focuses on the loved one she recalls before delirium; the one in the family portrait. What is important to Carmel [p13] is having experiences that support her mother’s dignity and reassert the presence of her speak-able mother. Like “A happier memory: a father” (Young, 2012), keeping secrets affirms her experience of her mother as again like to person she knows, loves and trusts; the person she knows from the family portrait.

... in some ways I was sort of glad she didn’t know, because I think it would have been really distressing for her, had she known what she was doing, because I don’t think she would have been happy that she did that. And plus it didn’t ever seem smart to rake over such an unhappy episode. I mean, you’d go there for a visit and talk about nice sunny day and the flowers were out and here’s a chocolate and whatever. You’d sort of try to keep the conversation to pleasant topics. You don’t sort of start dragging up her so called bad behaviour the day before.

(Carmel [p13] - I2 – p22)

Cathy [p4] describes how she thought it was remarkable and fortunate that her mother did not recall the stranger she was once delirium passed. It is a relief.

... But fortunately, she doesn’t remember any of it. Once she comes back, it never happened. So that distress can’t haunt her because she doesn’t remember it. (Cathy [p5] – I2 – p14)

Siblings Betty [p11] and Iris [p14] also describe, their mother as unaware of the way she changed during her many episodes of delirium. Having their mother back to being the person they know is a great relief and comforting, overriding any desire to share their knowledge of how she was.

... I think you’re just so grateful that she’s back again, you’re sort of living on that high again. I don’t think I did ever talk to her about that. (Betty [p11] – I1 – p24)

Focusing on their loved one’s return highlights the women’s relief that their loved one’s absence has ended for now. Acting so out of character is relegated to these women’s memories and to the land of secrets. The women’s secrets are however, ever-present and, for some women, they shape their relationships after delirium passes. As Cathy [p5] describes, she is compelled to share some parts of the stranger’s presence with
her mother. She hopes the little she tells will be enough to explain why she is guarded when they are together. For Cathy [p4] it is a balancing act. Keeping the worst parts of her experience secret is a burden she bears.

... she doesn’t like it, but I felt that she had to know, because she must notice a difference I think, in our attitude. As I was saying earlier it’s hard to go from one day in total madness to the next saying “Everything is fine”. Without you know, her understanding why we may be responding a bit differently to her. Not that we’ve told her every detail of it, of course, we have just told an odd bit here and there. (Cathy [p4] - I1 - p11)

The situation the women are in stops some women from telling their loved one about their experiences. As Gemma [p12] describes, she understood her father was dying and though she would like to tell him about the stranger’s presence she could no longer be sure that he would understand. Gemma’s [p12] knowledge of the stranger’s presence remains with her through his palliation and after he passed away.

... And it was very difficult to talk to him about anything that was really happening. If you said anything he just really--- I don’t believe, well, that’s it, you don’t know whether they actually take it in, or they don’t. [...] and we really didn’t tell him a lot. (Gemma [p12] - I1 - p5)

Other women have kept secrets from their loved ones before, the secret of the stranger simply adding to the burden of other secrets they carry. Beth [p7] describes how her husband had not been able to remember recent events for some time and how she had come to understand that she would have privileged knowledge of his life, including how he was when in delirium. She describes understanding that he can’t know his recent past for long. Sharing the stranger’s presence during delirium makes little difference when there is also dementia. As a wife and informal carer, Beth [p7] carries privileged knowledge as imposed secrets and as a burden that she has no choice but to bear.

**Review and Summary**

This chapter has presented the findings of the study. Through textual description and exemplars, the essential structure and meaning of experiencing delirium in an older loved one has been revealed as **Changing family portraits: Sudden existential absence during delirium**. To further reveal the essential structure of the women’s experiences
and more fully answer the research question the themes and sub-themes that constitute the experiences of the women have been described. *Changing family portraits: Sudden existential absence during delirium* shows how, during delirium, the familiar presence of the women’s loved one is *taken-for-granted* and how this presence suddenly becomes absence. During delirium the women’s loved one has a new presence, a stranger who appears suddenly and is strikingly different to the person the women know as their mother, father or husband. The absence of their loved one and presence of a stranger was all pervasive. Their loved one’s presence is revealed to be fragile rather than certain. The discussion also described how, with little control over what is happening, the women lived life holding on to their memories of their loved one, waiting and hoping for their familiar presence. Day to day life was a painful interplay between the loss of their familiar loved one, the presence of a stranger and their now uncertain future. Left to manage on their own, and without an explanation for their loss, the women tried to help their loved one but were unsure about what to do to; how to console the stranger and help their loved one to return.

In the next chapter the study findings are discussed in light of current research and theoretical perspectives, including consideration of family member experiences of absence when caring for a loved one with dementia and theoretical conceptualisations for losing a loved one’s self. The limitations of the study are then addressed, as are implications from the findings for health care practice and future research.
CHAPTER 7: DISCUSSION AND CONCLUSIONS
Chapter Introduction

In chapter one I argued that, in light of the prevalence and incidence of delirium, and by virtue of love, a sense of duty, roles or responsibilities, family members of older people are likely to encounter their loved one during delirium and the changes that ensue. I described an interest in, and concern for, family members who are with their older loved one during an episode of delirium and I identified that little has been known about family member experiences during this time. Whether or not family members are at home with their loved one or visiting them in residential aged care or acute hospital wards, it is important for health care staff to understand and respond to the experience of family members during this challenging and often difficult time. I argued that without an understanding of the perspectives of family members themselves, it is difficult for health care staff to respond with compassion, provide support and appropriately include family members in their older loved one’s care.

Based on these arguments, I set out to explore the subjective experiences of family members during their older loved one’s delirium and to elicit the meaning of their experiences. Through the application of existential phenomenology, informed by the philosophical views of Sartre (1943/2003) and Merleau-Ponty (1945/2002), an understanding of the experiences of the women in this study was gained. Choosing existential phenomenology to guide the study was influenced by the nature of the research question posed; “What is the lived experience of family members who are with an older person when the older person has delirium”? It was also influenced by the “fit” between the research question and the concerns of the existential philosophical perspective; with the study of human lived experience within the life context of each person, challenging taken-for-granted understandings of experience and drawing out meanings embedded in everyday human existence (Luijpen & Koren, 1969/2010; van Manen, 1990). Instead of viewing collected experiential accounts through theoretical frameworks, existential phenomenology guided a phenomenological way of thinking, enabling the development of descriptive texts which communicate the essential features of the women’s experiences. These features, or meanings, reach beyond the facts of the women’s experiences to an understanding of the existential or lived nature of being a family member of an older loved one during delirium.

As presented in the previous chapter, Changing family portraits: Sudden existential absence during delirium depicts the women’s experiences during their older loved one’s delirium. Existential absence (Sartre, 1943/2003) for the women in this study is experienced as the sudden absence of their familiar loved one, and the arrival of a
stranger. The meaning of existential absence for these women is further described by the theme Living the fragility of a loved one’s presence and the sub-themes Facing a loved one's existential absence and Living with a stranger, as well as the theme Living life holding on and the sub-themes Waiting for a loved one, In the dark, On the fringe but centre stage, On thin ice, and Keeping secrets. Like twigs in a bird's nest, these themes and sub-themes weave together to form a description of the women’s experiences as a whole, revealing the unexpected and distressing nature of existential absence (Sartre, 1943/2003) and how difficult it was for the women to cope and await their older loved one’s return. From this description, this thesis argues that by understanding the existential absence (Sartre, 1943/2003) family members experience during their older loved one’s delirium, and how difficult it is for family members to await their loved one’s return, health care staff have an opportunity to be attentive to family member experiences, to respond with compassion, provide support and appropriately include family members in their older loved one’s care.

In this final chapter the study findings are reviewed and considered. The existential nature of older person delirium for the women in this study is discussed, illustrating how existential phenomenology has provided a meaningful interpretation of the women’s experiences and contributed to our understanding. The main findings are also discussed with reference to previous work, so extending the discussion and locating the study findings within existing research and theoretical understandings. Throughout this discussion the women who participated in the study are like lead characters in a play; their descriptions are like performances, communicating existential meanings and so determining the direction of the discussion and the nature of work consulted. How the findings of the study add further to current understandings of family member experiences during an older loved one’s delirium is established as the discussion progresses. The limitations and strengths of the study are also discussed, followed by implications for health care practice and suggestions for future research.

**The Existential Nature of Delirium**

*Changing family portraits: Sudden existential absence during delirium* depicts the essential nature of the experiences described by the women in this study. This essence portrays how the presence of an older loved one as a familiar self is taken-for-granted in everyday life by the women, and how, during delirium, their familiar presence was suddenly displaced by their older loved one’s absence and a stranger’s presence. The word absence is derived from the Latin abesse, where *esse* means to be, and *ab* means away (Harper, 2012; Leder, 1990). Etymologically absence is a being-away of
something (Harper, 2012). Connecting with the notion of existential absence (Sartre, 1943/2003), absence depicts when something anticipated is experienced as missing or lacking rather than present. For the women in this study, their older loved one’s self, or spirit (Merleau-Ponty, 1948/2004), was formally present to their gaze (Merleau-Ponty, 1945/2002) however, during delirium, their spirit was unexpectedly missing. The women remained aware of being with their older loved one corporeally at a particular time, in a particular place and sharing a situation, but their co-presence had a unexpected and distressingly changed quality; a quality experienced as existential absence (Sartre, 1943/2003). In contrast to the notion of a family portrait, an image which evokes memories of a loved one’s familiar spirit, the women experienced their older loved one as no longer having the expected thisness for them (Sartre, 1943/2003). At the same time the women experienced the presence of a new self; a stranger. Shaking the women’s preconceptions about everyday life, experiencing existential absence (Sartre, 1943/2003) and the presence of a stranger revealed their loved one’s co-presence to be fragile and tenuous rather than assured. The literal absence of their older loved one and the non-familiar presence of a stranger was experienced by the women in this study as existential absence (Sartre, 1943/2003).

Certain qualities characterised the nature of the existential absence (Sartre, 1943/2003) experienced by the women in this study; it was unexpected, traumatic and pervasive. Unlike other losses some women had experienced during their loved one’s dementia, experiencing existential absence (Sartre, 1943/2003) was a shock; it was unforeseen rather than anticipated, sudden rather than insidious, unpredictable rather than predictable. Their older loved one’s absence came quickly and without explanation and was incongruous with their loved one’s continued corporeal presence in the world. It was difficult to comprehend; their absence was unrelated to their loved one’s physical death and seemed to break the unity of their older loved one’s corporeal presence and self. Though continuing to live, what was missing for the women was their older loved one’s familiar self; the women’s mother, father or husband.

Although existential absence (Sartre, 1943/2003) can be an everyday life experience, perhaps encountered as Sartre (1943/2003) describes when a friend fails to appear in a café, for the women in this study existential absence (Sartre, 1943/2003) was a profound experience. It was seen and felt as a major and frightening change to what they anticipated; distressing the women and dominating their experience during their older loved one’s delirium. As described by Sartre (1943/2003), their loved one’s absence haunted their experience and was real; absence was experienced by the women as their loved one’s familiar self being elsewhere. Being with their older loved
one was a painful contrast to the notion of a family portrait, an image of past familiar, happy and certain times. During delirium, existential absence (Sartre, 1943/2003) was the women’s being-in-the-world (Luijpen & Koren, 1969/2010), disclosing the essential nature of their experience.

**Familiar Presence and Existential Absence**

The women’s experience of existential absence (Sartre, 1943/2003) during their older loved one’s delirium drew attention to their being-in-the-world with others (Luijpen & Koren, 1969/2010), and how they had come to know their older loved one before the onset of delirium; through conscious awareness of their mother, father or husband as a special person in their life, and as someone who shared the world.

The women in this study were attuned to their older loved one as a familiar or known person; to the usual things they did, what they liked, how they felt, how they looked and how they related, understandings rich with subjective meanings crafted over time and through changing circumstances. They came to be with their older loved one during delirium with a past; a history of caring and relating. The women’s familiarity with their older loved one was, however, from an angle; a thisness for them (Sartre, 1943/2003) which reflected their positional way of knowing them as a daughter or wife. Sartre (1943/2003) argues that recalled appearances from past life, such as the women’s recall of their loved one’s familiarity, are not imagined. They are recalled when directing consciousness to their loved one such that their loved one is expected to be as given-now-as-in-the-past (Priest, 2001, p. 96). As Merleau-Ponty (1945/2002) says, memories of past perception or experiences are embodied and, when recalled, evoke the situation and reopen time lost.

As special people in the women’s lives, the women were also aware of their older loved one in situations as though a whole (Merleau-Ponty, 1945/2002, 1948/2004); as a person whose corporeal presence reliably embodied the loved one they knew so well. As Merleau-Ponty (1948/2004) says, their older loved one had a familiar “spirit that haunts the body” (p. 62); the spirit of their mother, father or husband. With this expected thisness for them (Sartre, 1943/2003), the women entered a situation in which their loved one had delirium and sought, as always and even though their loved one was unwell, to affirm their loved one’s presence as a whole person.

The women’s taken-for-granted understandings about their loved one acted as a background or horizon (Merleau-Ponty, 1945/2002) that shaped the women’s expectations and desires, and through which they related and experienced their
situation during their loved one’s delirium. However, during delirium and against this background, the women in this study experienced a sudden change to their loved one’s familiarity. Their loved one’s familiar presence was unexpectedly displaced by their absence and a stranger’s presence. Though the women expected their older loved one would be familiar and present, the person empathetically given to them through their look, gestures, speech and attitude (Merleau-Ponty, 1945/2002, 1948/2004) was unfamiliar and foreign. The ways their loved one acted engendered a shift in intentional conscious awareness; from the taken-for-granted way family members understood their loved one to the changed, malfunctioning and unfamiliar way their loved one acted during delirium and its foreignness. As described in the previous chapter, for some women it was a change in their loved one’s eyes; in the way they were different and no longer looked back at them when they met. For other women it was the way their loved one was abusive or talked nonsense, pulled at their pyjama buttons, chased butterflies or complained of children riding skateboards up and down the ward. Through unfamiliarity the women became aware of delirium having what Sartre (1943/2003) calls magical animistic qualities. What their loved one was doing and saying was odd, out of character, and not really usual for their older loved one or, for that matter, other people. Their loved one’s familiarity was missing and, for the women, the situation during delirium lacked (Sartre, 1943/2003) their mother, father or husband. Existentially conscious-being-in-the-world, or being an in-person (Luijpen & Koren, 1969/2010) defines life. Rather than physical death, the loss of their loved one’s “in-personness” defined their loved one’s absence and the fragility of their loved one’s presence in their world. Instead of being with their loved one during their illness, the women were unexpectedly separated from them and were with someone who was foreign and new; an in-stranger.

In this study experiencing a break in continuity between what was anticipated and lived was central to the women’s experience of existential absence (Sartre, 1943/2003). To expect a person is described phenomenologically by Sartre (1943/2003) as the manner in which we encounter and anticipate the world for us. He argues that when our expectations are not met, our situation lacks something for us and absence is lived (Sartre, 1943/2003). For the women in this study, how their loved one appeared in the world during delirium fell short of their expectations. Their world lacked (Sartre, 1943/2003) their loved one’s familiar self. As their loved one’s corporeal presence lacked (Sartre, 1943/2003) the spirit (Merleau-Ponty, 1945/2002) or self the women knew, loved and trusted, their older loved one had but a partial appearance (Sartre, 1943/2003). As described by Sartre (1943/2003) the women’s situation was in itself not
lacking. Rather, something was lacking (Sartre, 1943/2003) in the women’s experience during their loved one’s delirium. Their older loved one’s self was no longer bound to their corporeal presence; they were not where the women thought their older loved one’s self should be.

Before delirium, the women had experienced their loved one’s spirit (Merleau-Ponty, 1945/2002) and corporeal presence as intertwined and predictably available to them; as present as expected, familiar and as a whole. This past contrasted with the women’s experience during delirium, an experience where their familiar loved one’s spirit was incongruously displaced, and their loved one’s familiar corporeal presence was rebound such that it embodied (Merleau-Ponty, 1945/2002; Sartre, 1943/2003) the unfamiliar spirit (Merleau-Ponty, 1945/2002) of a stranger. As with the phenomenological distinction between object/body and subject/mind (Stewart & Mickunas, 1974), their loved one had a corporeal (or object) presence but the self (or subject) was missing. However, in contrast to the phenomenological notion of embodiment (Merleau-Ponty, 1945/2002; Sartre, 1943/2003), the women described the disembodiment of the self (or subject) from the corporeal (or object) presence; the perception of an incongruous separation of mind from body. The literal absence of the women’s older mother, father or husband and the presence of a stranger threatened the women’s taken-for-granted, every day or assumptive world. It questioned the women’s embodied understanding of their loved one and disclosed their loved one’s fragile and tenuous presence.

Even knowing that delirium was transient failed to prepare the women for their loved one’s absence during delirium; for the break in their taken-for-granted understanding of who their loved one was and for their loved one’s absent spirit and a stranger’s presence. When their older loved one’s delirium persisted or recurred, existential absence (Sartre, 1943/2003) also inhabited the women’s horizon (Merleau-Ponty, 1945/2002), reflecting the women’s fears or uncertainties about their loved one’s sustained or future presence. As expressed by Merleau-Ponty (1945/2002), and as for these women, the horizon guarantees the identity of their older loved one by distinguishing and disclosing other people as familiar or unfamiliar.

A Stranger’s Presence

The women’s experience of existential absence (Sartre, 1943/2003) during their older loved one’s delirium also drew attention to their intentional conscious awareness of a the new presence; of the in-stranger. The person they were with, the person given to them during delirium through their loved one’s look, gestures, speech and attitude...
(Merleau-Ponty, 1945/2002, 1948/2004), was unfamiliar and foreign. Illustrating the women’s attention to the body of other people sharing the world, at the fore of their experience was the stranger’s peculiar ways, loss of self-control and their presence in another world. The women saw how the stranger acted and heard what they said; behaviours that were unexpected, bizarre, and shocking, or in contrast, closed, quiet and distant. Their loved one’s hallucinations, by virtue of their nature, were not accessible; for the women they were not real, disconnected from the natural world but at the same time perceived by their older loved one as real (Merleau-Ponty, 1948/2004). For the women in this study their loved one’s hallucinations transformed them into a stranger who inhabited an inaccessible other world.

Through their loved one’s appearance, their loved one’s corporeal presence compelled and held the women’s conscious awareness, whilst other aspects of their experience were indistinct and fell into the background. Their loved one’s corporeal presence was figural and became an object of the women’s scrutiny; the foreignness they encountered exemplified the otherness of the stranger and how changed the women’s loved one had become. Otherness was a quality which was incongruous with the person the women knew and loved; it was distressing, worrying and at times frightening. As described in the previous chapter, the stranger was “childlike”, “out of it”, “off their trolley”, “mad as a hatter” and was “not of right mind”. Otherness magnified the women’s experience of lack (Sartre, 1943/2003) and, though their loved one had a continued corporeal presence, existential absence (Sartre, 1943/2003) pervaded their experience and emphasised the seriousness of their situation. Even when delirium was temporary, or when the women had encountered changes in their loved one from dementia, the familiar presence the women expected was opposed by their loved one’s absent spirit (Merleau-Ponty, 1945/2002) and a stranger’s presence.

The use of chemical and physical restraint to contain the behaviour of some older loved ones during delirium, as noted in the previous chapter, suggested to the women that other people sharing the situation also experienced the stranger’s behaviours as foreign. It suggested how inappropriate and unacceptable the stranger’s behaviours were to health care staff working in care environments; the stranger exhibited bizarre behaviours that went beyond what was appropriate for people in their care. Other people within the women’s social world deemed the stranger’s behaviours as needing to be reined in. For the women, holding the stranger down and using restraints took away any remaining semblance of the stranger’s dignity and humanness, making it hard for the women to be present and to perceive the stranger as theirs or as human.
Experiencing the loss of the stranger’s dignity and humanness was highly distressing for some women in this study.

Though the stranger’s behaviours were odd and out of place, the women’s experience of their loved one’s absence was not shared by health care staff, portraying the uniqueness of each person’s perception. Merleau-Ponty (1945/2002) argues that what appears in perception is always from the vantage point of the subject perceiver, varying in tune with factors such as the angle, time, context, background and orientation of the perceiver. Each person’s view and experience is therefore always egocentric and how the world is lived for them. For health care staff the women’s older loved one was likely to be who they were “now” during delirium, having different familiarity expectations to the women. Existential absence (Sartre, 1943/2003) in this study was uniquely lived from the women’s perspective, no matter whether they were at home, at hospital or residential aged care, and no matter if their older loved one already had dementia.

Some women searched for recognition while their loved one was a stranger; they wanted and needed to be familiar and known. For some women the person they were with during delirium was so much a stranger that they no longer recognised the women as familiar to them. Reflecting Merleau-Ponty’s (1962; 2004) view that co-existence is fluid and that our communion can be lost when the other’s gaze is objectifying or when the other person turns away from life in a shared world, these women felt unknown by their older loved one during delirium. Expressed as an inhuman gaze by Merleau-Ponty (1945/2002) and the look by Sartre (1943/2003), their loved one’s look-back-at-me was from the outside; it was distancing and ended co-existence as subjective beings in the world. Being unknown was upsetting and painful, accentuating the women’s experience of existential absence (Sartre, 1943/2003).

**Holding on to Familiar Memories and for Familiarity**

Suddenly experiencing existential absence (Sartre, 1943/2003) during delirium, the women in this study held on to their memories of their familiar loved one and, despite perceiving the stranger’s embodiment, anxiously awaited their loved one’s return. Reflecting Merleau-Ponty’s (1945/2002) view of intentionally, the women’s close ties to their older loved one were intentional threads that held them to their mother, father or husband though absent. Though the women were with a stranger the call of their loved one was revealed by the women’s search and wait for their familiar loved one. As explained by Sartre (1943/2003) the women’s experience of holding on reflects the personal significance of the women’s situation; their desire, hope and expectation that their situation would be righted; that the in-stranger would be temporary, their loved
one’s absence would end and their loved one would return to how the women remembered. The women looked to the future and were eager to again share the world with their mother, father or husband; a presence that matched past *taken-for-granted* ways of knowing their older loved one. Revealing the women’s ongoing attention to the body of other people sharing the world, they watched the stranger they were with, waiting and hoping their world would again be as *expected* and *desired* (Sartre, 1943/2003). As suggested by Sartre the women’s emotions coloured *things*, making them perceive *things* in the world in a particular way (McCullock, 1997). Through the women’s *gaze* (Merleau-Ponty, 1945/2002), an *outside* view (Luijpen & Koren, 1969/2010), the women sought a familiar *thisness* for them (Sartre, 1943/2003) that signalled an end to their loved one’s absence; that their loved one was once again *in-person* (Luijpen & Koren, 1969/2010). As with Merleau-Ponty’s notion of *looking familiar* (Merleau-Ponty, 1945/2002), familiarity for the women was not captured only through the perception of a set of properties. Rather, for their loved one to look familiar they needed to feel familiar, a perception in which the feelings of unfamiliarity or familiarity infuse and alter the person looked at (Romdenh-Romluc, 2011). The feeling of familiarity is inseparable from the person perceived by the women. The women hoped their loved one would return and their experience would align with the memory of the loved one evoked by their family portrait. During delirium their family portrait was a reminder of past more familiar and predictable times and stood in painful contrast to being with a stranger.

For the women in this study existential *absence* (Sartre, 1943/2003) had a temporal quality. When delirium set in, not knowing if their experience of existential *absence* (Sartre, 1943/2003) was temporary or if it would be permanent created uncertainty about the future. The women were unsure how long they would have to *hold on*, waiting and suffering the pain of their loved one’s absence.

*Holding on* was made harder for the women in this study by the suddenness and unpredictability that surrounded delirium, creating uncertainty about their loved one’s return. Existential *absence* (Sartre, 1943/2003) for some women ended as unexpectedly and abruptly as it began; coming and going with a jolt. Other women experienced an end to their loved one’s absence only to then go on to encounter delirium’s return and repeated experiences of existential *absence* (Sartre, 1943/2003). For these women existential *absence* (Sartre, 1943/2003) formed part of their *horizon* (Merleau-Ponty, 1945/2002), each and every day having the ever-present possibility of delirium and suddenly re-losing their older loved one’s self. Uncertainty about their loved one’s future presence remained even though they were well again, adding to the
women’s experiences of the fragility of their older loved one’s co-presence in the world and their loved one’s changeable portrait.

Understanding that their loved one’s presence could become absence when delirium returns, the women were watchful and on guard; they directed their conscious awareness to their loved one, looking to confirm their thisness (Sartre, 1943/2003) or the tell-tale signs of their loved one’s absence. For yet other women their experience of existential absence (Sartre, 1943/2003) during delirium was prolonged; their loved one’s absence lingered and the stranger remained, day after day. With no certainty about when, or if, their loved one would ever return, and little control over what was happening, holding on for an end to their loved one’s absence was arduous. Experiencing ongoing existential absence (Sartre, 1943/2003), the women confronted a view of the world that was at odds with the future that should have been. The person they loved and who was familiar to them was in their past, becoming the facticity of their life as already lived (Sartre, 1943/2003) and recalled from prior family portraits. These women lived a “now”, and faced a future, shared with an in-stranger.

Whilst immersed in their loved one’s absence and the presence of a stranger, the women turned to other people in their world and sought explanations for what had happened. With little understanding of the women’s perspective the few explanations health care staff offered, those concerned with infection, bowel obstruction, surgery, delirium, intravenous lines and medications, were imperfect and failed to connect with the women’s experience. Though Merleau-Ponty (1945/2002, 1948/2004) argues that consciousness, or experience, includes an intentional awareness of other people and the intersubjective relationship of one person’s existence to other human existences in the world (Merleau-Ponty, 1945/2002), the natural empathy which Merleau-Ponty (1945/2002, 1968) argues takes up the affective responses of other people sharing the world, were lost. The women’s perspective was missed, underappreciated or unknown by health care staff who shared the women’s situation. With little explanation for what they experienced holding on for their loved one’s return was like being left in the dark.

During their loved one’s absence the women were prevented from sharing what they knew about their loved one’s health and, for some, how prior delirium had unfolded. Often dismissed and at times belittled, the women were marginalised as care was decided and delivered by health care staff with little consultation. The women’s experience contrasted with what they thought their relationship would be; they entered their situation with an expectation that they would be valued, that health care staff would listen, they would have a respectful reciprocal relationship with health care staff
and that the staff would know how to care for their loved one. However, the women in this study experienced health care staff as distant and disengaged, having concerns that seemed different to their own. In their relationships with health care staff the women felt alone and marginalised. Whilst the women anticipated a relationship which Merleau-Ponty (1945/2002) describes as beside me and in a reciprocal relationship with me, what they experienced was akin to Sartre’s (1943/2003) alienation in relationships through being looked at. With a loss of reciprocity holding on for their familiar loved one was a path taken alone.

Watching health care staff have difficulty managing the stranger’s behaviours eroded the women’s trust in these staff members. Rather than finding reassurance and relief, the women were troubled and frustrated whilst living life holding on. Despite being marginalised by health care staff, the women persisted in being present and cared when and how they could, pushing other day to day concerns into the horizon (Merleau-Ponty, 1945/2002). They felt the emotional hold their older loved one had on them and felt caught; responsible for helping when the care of others seemed to not be enough. With little guidance in how to care, and unsure what to do, caring was like starting from scratch; all trial and error. Being with a stranger and caring created a completely new routine. Though their love, conscience and family roles called on the women to be with their loved one, they found it confronting and hard to be present and encounter a stranger. At times they watched on and felt helpless to console the person they were with. Though their loved one was absent and it was difficult for the women to be with a stranger, caring helped to keep their older loved one safe and helped the women to hold on to the possibility of their familiar loved one’s return.

Some women continued to hold on when delirium passed; keeping the stranger they encountered a secret from their older loved one. The stranger, the facticity or way that the women perceived their loved one to be from the outside (Luijpen & Koren, 1969/2010), was too odd and out-of-character to be fully revealed. The women held back what they knew of the stranger, protecting their older loved ones from knowing how other people had seen them from the outside (Luijpen & Koren, 1969/2010). Keeping secrets, though burdensome at times, affirmed the women’s familiar loved one; the person the women knew from their family portrait rather than the oddity of the stranger.
Loss of a Loved One’s Self During Delirium: Past Findings

At the core of the women’s experiences during their older loved one’s delirium was sudden existential absence (Sartre, 1943/2003). The changes that delirium brings to the older person mean that their loved one was suddenly unfamiliar; they seemed to inhabit a different world and behave in ways that are out of character and even bizarre (American Psychiatric Association, 2013; Stenwall, Sandberg, et al., 2008). Like this study, Stenwall, Sandberg et al. (2008) describe family member experiences of rapid and unexpected changes in the older person. Though their loved one’s corporeal presence remains, family members in both studies describe their older loved one as unfamiliar; either absent or lost, creating concerns about their future presence. Absence and concurrent corporeal presence in both studies is described as contradictory, confronting and confusing. As described in the findings of this study, and as previously reported (Stenwall, Sandberg, et al., 2008), the older person with delirium is not themselves and was not reliably embodied. In both studies family members describe having strong emotional responses to the experience of absence or loss; they are shocked and distressed. The presence of a person who is unfamiliar or a stranger to family members serves to emphasise their loved one’s absence. As with studies which explore the experience of family members who are with an older loved one during delirium (Stenwall, Sandberg, et al., 2008), Greaves et al. (2008) describes how family members of patients with advanced cancer also experience the loss of the person they know, and being with an unknown person during delirium. Distress is also a finding common to this and other studies considering family member experiences during their older person’s delirium (Bull, 2011; Stenwall, Sandberg, et al., 2008), as well as studies reporting experiences of family members of advanced cancer/palliative care patients with delirium (Breitbart et al., 2002; Bruera et al., 2009; Cohen & Pace, 2009; Greaves et al., 2008; Morita et al., 2004; Namba et al., 2007). Experiencing the delirium of a loved one is difficult for family members; in particular it is difficult when their loved one becomes a stranger to them.

Studies reporting delirium experiences for family members of patients in palliative care and advanced cancer (Bruera et al., 2009; Cohen & Pace, 2009; Greaves et al., 2008; Morita et al., 2007; Morita et al., 2004; Namba et al., 2007), like those for delirium in older loved one’s (Stenwall, Sandberg, et al., 2008), report unusual and unexpected behaviours. In contrast to the findings in this study and other reported findings related to older people and delirium (Bull, 2011; Stenwall, Sandberg, et al., 2008), some family members of patients with advanced cancer described the changes to their loved one as
being good, a normal reaction or as expected because of their medications (Cohen & Pace, 2009). This possibly reflects different family member expectations when a loved one’s diagnosis is known and death is anticipated, or possibly the influence of care philosophies in end of life care settings, perhaps differentiating nuances of family member experiences of absence (Sartre, 1943/2003) or loss in different care settings.

During their older loved one’s absence, the women in this study described holding on for their loved one’s return. Like this study, Stenwall, Sandberg et al (2008) describe how family members search for their loved one’s familiar presence and hope they will return, even though they are unsure how long their loved one’s unfamiliarity will last. When with their loved one during delirium, family members in Stenwall, Sandberg et al.’s (2008) study, like those in this study, felt their loved one’s familiarity and unfamiliarity was unpredictable, were unsure about what to do to help and found being with their loved one difficult and tiring. A need to re-connect with the absent or lost person is a finding common to this and other studies (Stenwall, Sandberg, et al., 2008), including those reporting on experiences of family members with advanced cancer/palliative care patients with delirium (Braitman, 2003; Cohen & Pace, 2009). Like some women in this study, Cohen and Pace (2009) describe how some family members of advanced cancer patients fear that delirium will remain until their loved one dies, taking away the chance to say goodbye.

Like the findings reported by Stenwall, Sandberg et al. (2008), the women in this study experienced difficulty in understanding what was happening, however the women in this study also described a gap between explanations offered by health care staff and what they needed explained; they felt kept in the dark about what was causing their loved one’s unfamiliarity and what they were experiencing. In addition to describing medical causes, delirium characteristics, and how family can help, the women in this study needed the existential absence (Sartre, 1943/2003) they experienced acknowledged and taken into account during their older loved one’s care.

Unlike the findings reported by Stenwall, Sandberg et al. (2008), the women in this study felt disregarded by health care staff during their older loved one’s delirium. Also unreported in previous studies is how the women in this study continued to hold on to the person who is familiar to them once their loved one had returned, watching for sudden changes to their familiarity and keeping their loved one’s past unfamiliar behaviours a secret. The varied experiences of family members during their older loved one’s delirium in this study has highlighted potential differences between family
member experiences during delirium in older people and experiences during palliative or advanced cancer care.

**Loss of a Loved One’s Self During Delirium and Current Theory**

Experiences of losing a loved one’s self have previously been described by family members of loved ones who suffer chronic or progressive changes in their health (see Chapter 2: Literature Review). These experiences have subsequently been considered in theoretical literature, resulting in the experience of losing a loved one’s self being conceptualised as a specific type of non-death loss; primarily as ambiguous loss from psychological absence (Boss, 2006), non-finite loss (Schultz & Bruce, 2005), and psychosocial death (Doka & Aber, 1989) (see Chapter 2: Literature Review). These concepts capture the experience of perceiving a person to have a corporeal presence and to be alive, only to be absent emotionally, cognitively or in inner essence. Like Merleau-Ponty’s (1948/2004) spirit, in these concepts the psychological essence, individual personality or self is missing (Doka & Aber, 1989); an experience that Doka and Aber (1989) suggest is like having a loved one’s body invaded by “mind snatchers” [or a stranger] (p. 188). Though primarily drawn from experiences during chronic changes to a loved one’s health, these concepts have qualities in common with the women’s experiences of existential absence (Sartre, 1943/2003) in this study, and the experience of loss and unfamiliarity previously described by Stenwall, Sandberg et al (2008). In the following discussion the similarities and differences between these concepts and the women’s experiences during their older loved one’s delirium are presented.

According to Boss (1999, 2006) and Doka and Aber (1989), family members who experience losing a loved one’s self, like the women in this study, have to deal with a loss that is ambiguous; it is a “goodbye without leaving” (Boss, 1999, p. 45). Like the women’s experiences, the loss of the perception of a person’s self is a profound change from the everyday familiar and taken-for-granted way other people are perceived; they are no longer as they once were and the qualities of the person with whom family members are attached are no longer present (Doka & Aber, 1989). Similar to Sartre’s (1943/2003) notions of expect and lack, Bruce and Shultz (2001) argue that loss [lack] begins with an individual’s assumptive world; with their expectations, hopes and wishes.

Similar to Doka and Aber’s (1989) psychosocial death, the sudden and dramatic nature of the women’s experience of losing their loved one’s self radically affects the women’s
lives; it is distressing and is difficult for them to endure. Also like the experiences of the women in this study, the loved ones expected by family members are no longer within reach (Boss, 2006). Consistent with the consequences Boss (1999, 2006) describes for ambiguous loss, the absence the women experience, and their experience of a stranger’s presence, creates confusion about the status of their familiar loved one within their relationships and within the family. According to Boss (2006), those who experience ambiguous loss have to deal with a loss that is not definitive. With a focus on the ambiguity of loss, Boss’s (1999, 2006) notion of psychological absence is concerned with the ambiguity in family membership boundaries when it is difficult for family members to determine who is in and who is out of the family system. Because reciprocal relationships and a clear presence are lost, Boss (2006) argues that psychological absence distresses family members no matter how healthy or resilient they are. The suddenness of losing their loved one’s self and the stranger’s foreign behaviours seemed to intensify the women’s distress in this study, a quality consistent with the experiences of relatives in the study reported by Stenwall, Sandberg et al (2008).

Along with the loss of a loved one’s self described by family members in this study, there are consistencies between the women’s experiences of *holding on* and conceptualisations of psychological absence (Boss, 1999, 2004, 2006), psychosocial death (Doka & Aber, 1989, 2002), and non-finite loss (Bruce & Schultz, 2001). For the women in the study, being with a person who shifts somewhat unpredictably back and forth from being familiar to a stranger adds to the uncertainty that surrounds their loved one’s recovery and, as described by Boss (1999, 2006), to the ambiguous nature of their loved one’s absence and presence. For Boss (2006), the ambiguity in the loved one’s presence is inherently filled with anxiety because of the trauma that stems from a sudden change from the ordinary dependable way things are to a profoundly altered state that cannot be or is difficult to rectify (Boss, 2006). When *holding on* for their loved one to return, the women in this study experienced moments in which their loved one was again familiar, a presence which, as Bruce and Shultz (2001) describe, creates a “chameleon like” quality to the women’s experience. This oscillating or shifting presence is also consistent with Doka’s (2000) view that, similar to Sartre’s (Sartre, 1943/2003) notion of partial lack, psychosocial absence can fluctuate with a loved one’s condition and be perceived as partial or total. Bruce and Shultz (2001) argue that although people may contemplate the possibility of losing a person within a relatively predictable future, a naïve reliance on the *taken-for-granted* world means that events such as the sudden loss of a loved one’s presence come as a shock. Similar to
Bruce and Shultz’s (2001) view that a person’s sense of balance is disrupted by sudden events that threaten *taken-for-granted* views of the world, the women in this study described feeling shocked, left without explanations and unsure what to do.

For some women in the study their loved one’s absence had no foreseeable end and remained; relentless and inescapable. Their loved one’s absence dragged on, having similarities with the enduring nature of Boss’s (1999, 2006) concept of psychological absence, and Bruce and Shultz’s (2001) concept of non-finite loss. As described by Boss (1999, 2006), psychological absence is beyond the women’s control. When experienced, family members are left with an unresolvable loss, and the ongoing ambiguity and stress of living life with loss (Boss, 1999, 2006). As evident for some women in this study, being unable to resolve their loved one’s absence was painful, confusing, sad and distressing. Without the certainty of a known chronic condition, the women had to wait and see what would happen. As noted by Boss (2006), the trauma of their loved one’s absence dragged on, having what Bruce and Shultz (2001) describe as a lingering and inescapable quality.

However, the experience of other women in the study departs from Bruce and Schultz’s (2005) concept of non-finite loss and Boss’s (1999, 2004, 2006) concept of psychological absence. By primarily referring to these losses as incremental, enduring and having no clearly marked conclusion, these concepts consider the loss of a loved one’s self to be sustained or insidious and more apparent with the passage of time. However, for the women in this study, and that reported by Stenwall, Sandberg et al (2008), absence during delirium was sudden and often unexpected, taking their older loved one away all at once and catching family members somewhat by surprise. In addition, for some women in this study absence comes completely and resolved just as completely; their older loved one returning to how they remembered and as depicted in their family portrait. *The stranger* now gone, some women in the study described an end to *holding on* for their loved one’s return and the pain of their loved one’s absence, even if delirium remained in their *horizon* and recurred again. Absence for these women was a shock; sudden and inescapable, but temporary and often brief. Their older loved one was present once more and as before; often as though nothing had transpired. Even when dementia was present the return of the women’s loved one was clear. Though their experience had been distressing, an end to their loved one’s absence was a relief; albeit only a temporary situation for some women and though they were *on thin ice* watching for and anticipating absence again.
Though delirium is medically classified as a reversible condition (American Psychiatric Association, 2013), the women in this study experienced losing their loved one’s self for different periods of time. Therefore of particular interest for the findings of this study is Doka and Aber’s (1989) view that the underlying condition or situation leading to the loss of a loved one’s self may lie on a continuum of reversibility to irreversibility. This idea best describes the range of family member experiences during their older loved one’s delirium in this study and accounts for experiences of absence that end, recur and persist. The qualities of ending as well as persisting absence suggests the experiences of the women in this study have different qualities to those of family members with loved ones who have conditions which are chronic or insidiously progressive. For example, family members of older people with ADRD describe losing their loved one’s self across the progressive stages of ADRD, an absence that begins subtly, develops gradually and drags on to a point where the person becomes unrecognisable (Betts Adams et al., 2008; Collins et al., 1993; Gillies, 2011; Orona, 1990; Sweeting & Gilhooly, 1997). For family members of older people with ADRD absence sneaks up on them, is incremental and long term; for these family members life may seem like a funeral that never ends (Aronson & Lipkowitz, 1981). The literature on family member experiences of losing a loved one’s self during ADRD has been mainly related to ambiguous loss during psychological absence (Boss, 2006) and non-finite loss (Schultz & Bruce, 2005). This contrasts with the experiences of the women in this study, those that have a better conceptual fit with Doka and Aber’s (1989) psychosocial death.

In addition to developing concepts which describe the loss of a loved one’s self during chronic conditions, there is an associated body of literature which theorises family member mourning and grief in these situations. This literature argues that family members or carers endure a deep personal loss and also complicated grief reactions when they experience a sustained change in their loved one’s self (Boss, 1999, 2004, 2006; Bruce & Schultz, 2001; Chan et al., 2013; Doka, 1987, 2010, 1989b; Doka & Aber, 1989; Holley & Mast, 2009; Rando, 1986b; Walker et al., 1995). Boss (2006) and Doka and Aber (1989) argue that accepting psychosocial death or psychological absence is more difficult than losses from physical death, as the person’s continued daily physical presence in life denies the reality of their absence. In addition, because the loss rarely receives recognition from others as real, Doka (1989a, 2002a) argues that the grief experiences cannot be openly acknowledged and become disenfranchised (see Chapter 2: Literature Review).
The women’s experiences of losing their older loved one's self during delirium radically affected the women's lives. Often realising separation from their loved one before a tangible threat to life, their older loved one’s sudden absence was distressing and difficult for the women to endure. However, it is not clear if loss related grief and mourning was the origin of the women's distress during delirium, and hence was related to normal or complicated grief and mourning. For example, disenfranchised grief (Doka, 1989a, 2002b) (see Chapter 2: Literature Review).

It is possible that the experience described by some women in this study included grief and mourning. Consistent with Doka's (1989a) notion of disenfranchised grief, there was little external recognition of the women’s experiences of losing their loved one's self nor recognition of how deeply saddened the women were by their loved one’s absence, even when this was prolonged. For these women the suddenness of the onset of their loved one’s absence was in the past and the shock of experiencing their absence had abated; they remained distressed and were immersed in waiting and hoping for their loved one to once again be as they were prior to delirium. As Doka (2000) suggests, these women found it hard to cope with their loved one being alive in a different way, and to be with other people who perhaps did not understand their loss nor why it was distressing and mourned. This suggests that the experiences of some women may have similarities with Doka’s (1989a) “silent sorrow” during disenfranchised grief. However, it is not clear if the origin of the women’s sadness and distress was a lack of recognition of their loss by others, or whether there was a lack of self-acknowledgement that enabled the women to “cover over” their own loss and grief. This later dimension of disenfranchised grief is referred to by Kauffman (1989) as self-disenfranchisement; where shame or embarrassment about the views of other people in the person’s world impedes self-acknowledgement of loss (Doka, 2010). Perhaps for the women in this study, a fear of openly expressing their distress when their loved one was alive and acutely ill during delirium, or perhaps embarrassment or humiliation from their older loved one manifesting uninhibited and inappropriate behaviours; behaviours that isolated family members from possible support in health care settings.

Although some women experienced their loved one’s absence as prolonged and possibly experienced disenfranchised grief it is also possible that some women experienced anticipatory mourning (Rando, 2000c) (see Chapter 2: Literature Review). Some women in the study experienced their loved one’s absence at a time when their loved one’s care was changed to palliative care and possibly when the women were also mourning age related losses observed in their older loved one (Kowalski, 1986).
Although some women experienced their loved one’s absence as dragging on and possibly experienced disenfranchised grief (1989a), other women in the study experienced absences that came and went unpredictably over time. In these situations the women were watchful, as though anticipating their loved one’s absence and trying to “cut it off at the pass”. Though delirium was not a life threatening illness, for these women their loved one’s absence was distressing when it occurred. However, they came to know what delirium was and that, after a while, their loved one usually returned.

Still other women in this study experienced an end to the loss of their loved one’s self; their situation righting itself often just as suddenly as it began. These women described the shock of suddenly losing the presence of their familiar loved one and were distressed, but they were relieved when their loved one returned so quickly; they were back to being mum or dad again and life went on. For these women there was little time for sadness during episodes of delirium. Consistent with these women’s experiences Boss (2006) acknowledges that, though losing a loved one’s self distresses family members no matter how healthy or resilient they are, absence of a loved one’s self does not have to be problematic. Though it will test family resilience, Boss (2006) suggests that this experience mainly becomes problematic when family members experience feelings of hopelessness, depression and passivity, or feelings of ambivalence that lead to guilt, immobilisation and anxiety, perhaps suggesting that grief is more likely if the experience is lengthy rather than brief. Even so Boss (2006) remains optimistic that family members, like some women in this study, do and can live well although they experience the loss of their loved one’s self.

Although the absence experienced by family members during their older loved one’s delirium in this study has similarities with family member experiences during chronic conditions such as ADRD, aspects of their experiences are also different, distinguishing these encounters. The similarities and differences between family member experiences during their older loved one’s delirium and the concepts of psychological absence (Boss, 2006), non-finite loss (Schultz & Bruce, 2005), and psychosocial death (Doka & Aber) have not previously been described in the literature (see Chapter 2: Literature review). Nor has it been suggested that Doka and Aber’s (2000; 1989) notion of psychosocial death, with the qualities of reversibility/irreversibility and partial marked change, has strong similarities with the experiences of family members during an older loved one’s delirium. It needs to be noted however that whilst absence of a loved one’s self is a quality shared with Doka and Aber’s (1989) psychosocial death, the women’s experiences in this study seem to diverge from this
concept when considering Doka’s (1989a, 2002b) associated notion of disenfranchised grief and Rando’s (2000b) notion of anticipatory mourning. Whilst both disenfranchised grief (Doka, 1987) and anticipatory mourning (Rando, 2000b) are possible experiences of the women in this study, they do not adequately account for the experiences shared by all the women. The variation evident in the women’s experiences suggests there is a need for a better conceptualisation of grief and mourning during family member experiences during an older loved one’s delirium, perhaps one that is in tune with Doka and Aber’s (1989) notion of reversible and irreversible psychosocial absence and Doka’s (2000) notion of partial psychosocial absence. Though new, these arguments and the distinction between family member experiences during delirium and chronic conditions such as ADRD are supported by the women’s experiences and findings in this study, potentially extending our understanding of family member experiences of losing a loved one’s self or absence during delirium, and suggesting implications for health care practice and future research.

**Practice Implications**

The findings of this study, with that of Stenwall, Sandberg et al (2008), highlight the profound impact of family member experiences during their older loved one’s delirium and establish the importance of health care staff appreciating family member experiences, responding with respect and compassion, and sensitively including family members in their older person’s care. Although the significance of this study will only be known after dissemination amongst health care staff who care for older people, I believe it has made a significant contribution to understanding the experiences of family members during their older loved one’s delirium. How the meaning of the women’s experiences in this study contribute to action sensitive knowledge (van Manen, 1990), and influences future health care practice, is however described in the following sections.

The findings of this study point to an ongoing need to apply existing approaches to older person care, across care contexts, which address both older person and family member concerns. For example, partnership (Li et al., 2000) or relationship centred approaches (Bridges et al., 2010) to care as noted in Chapter 1: Study Introduction. There is an ongoing need for health care staff to appreciate and respond to the experiences and concerns of the older person and their family members when changes, such as delirium, occur in the older person’s health. As has been shown in this study and others (Sorensen Duppils & Wikblad, 2007; Stenwall, Jönhagen, et al., 2008; Stenwall et al., 2007; Stenwall, Sandberg, et al., 2008), the perspectives of
family members and older people will differ during delirium. Understanding each perspective potentially enables health care staff to focus on each person’s experience and appreciate their unique concerns. Often the experiences of family members are missed, ignored or undervalued by health care staff; be that because family members are not invited to speak about themselves or staff members underappreciate delirium’s impact on family members and themselves (Agar et al., 2012; Dahlke & Phinney, 2008; Lou & Dai, 2002; Rogers & Gibson, 2002; Schofield et al., 2012). In addition, Hallberg (2002) suggests that health care staff encounter people in difficult situations every day and that their familiarity with these situations can lead them to lose sight of the uniqueness of other people’s perspectives. Although it is understandable that health care staff find caring for older people during delirium difficult and distressing (Morita et al., 2004), their role in health care calls on them to be able to support the older person’s family members. In the provision of contemporary health care it is not acceptable to either dismiss the profound impact of an older person’s delirium on family members or expect family members to provide care without recognising the impact of their experience. Given the experiences of the women in this study, it is however unlikely that one strategy would support all family members, suggesting a need to set aside assumptions and tailor support to individual family member experiences and concerns.

Though the experience of losing a loved one’s self, or the notion of absence (Sartre, 1943/2003), does not have to be devastating or a problem for family members (Boss, 1999), the distress experienced by family members during an older loved one’s delirium and the consistency of this finding with previous research (Cohen & Pace, 2009; Morita et al., 2004; Stenwall, Sandberg, et al., 2008), suggests that family members may benefit from the offer of interventions that are supportive and help to mitigate distress. Understanding that family members can experience their familiar loved one as absent during delirium suggests that it is important for health care staff to consider whether family members perceive their known person to be absent and, if so, to integrate understandings of this experience into their interactions with, and support for family members. Consistent with the approaches taken by Bridges et al. (2010) and vom Eigen et al. (1999), family members may benefit from emotional support through empathetic interest in them as people and inviting them to voice their concerns about what is happening to them and to their older loved one. Making time to be with family members and providing opportunities to express feelings or concerns, providing information or explanations, and talking about how they are coping with the changes they perceive in their older loved one, may help to answer questions, reduce
uncertainty and distress, and sustain hope as family members wait for their loved one to return. Health care staff should be mindful that family members may be experiencing losses that are not readily observable to them. Providing opportunities for family members to talk about what their experience is like may serve to “tune” health care staff into family member experiences of loss. Sensitively acknowledging their loved one’s absence may validate what family members experience and minimise self-blame for their loved one’s circumstances (Boss, 2006). Family members may need help to name the absence they experience and to realise how they feel (Boss, 1999). Doka also suggests that naming what family members experience helps to legitimate what they feel. As Boss (2006) and Doka (1999) suggest, what family members experience may not seem real, seem insignificant or feel invalid as their loved one has a continued corporeal presence. Health care staff may be the only ones in the family member’s situation who have the potential to know about absence during a loved one’s delirium, and who can help family members to understand what they are experiencing. Failing to explore family member experiences with family members themselves may imply their loved one’s absence is unimportant or not real. Non-judgemental listening and open discussion may be the best tools for understanding each family member’s experience and for compassionate and meaningful emotional support. As with family members who experience losing a loved one’s self when with their older loved one during ADRD, helping family members to recognise qualities of their familiar loved one may help to reduce the distress they feel and to recognise the humanness of the person they are with (Kitwood, 1997; Stenwall, Sandberg, et al., 2008). Incorporating these strategies to support family members would be an expression of health care staff compassion and caring. They have the potential to lower feelings of distress and help family members to feel supported and understood during an often confusing and distressing time, perhaps enhancing their resilience or improving their coping. Being supported and understood might assist them to be with their loved one during delirium and help them to assist with care. Understanding family member experiences of absence during delirium can help health care staff to know preferences for care involvement and to consider when, or if, it is appropriate to request or encourage family involvement in their older loved one’s care during delirium.

The distress experienced by family members also suggests there is a need for continuing support when delirium persists and after delirium has passed, so helping family members to understand their experience and cope with future or ongoing loss of their familiar loved one. This is consistent with van der Veld (2010), who emphasises the importance of offering opportunities to discuss experiences after delirium resolves
and providing additional information and explanation about delirium even though it has passed. When delirium persists and an older loved one's absence is ongoing, family members find it hard to wait and become unsure if their loved one will return. They can feel impatient as recovery may be slow and unsure. When delirium persists loss counselling approaches should be considered, somewhat similar to approaches used to address anticipatory mourning and disenfranchised grief for family members who care for older people with ADRD (Boss, 2006; Bruce & Schultz, 2001; Doka, 2004; Doka & Aber, 1989; Rando, 2000c). Access to informal peer support groups, similar to those used for carers to loved ones with ADRD (Frank, 2008), may be supportive for family members of older loved ones with persistent delirium. Having contact with other family members who have or are experiencing a similar loss may help to mitigate family member distress and sadness. These approaches recognise the trauma family members face during their loved one’s persistent delirium and their need to learn to live with their loved one's absence while also sustaining hope for their loved one's return.

The women in this study expressed a need for information to help them to understand what was happening to them, as well as their older loved one. Boss (1999) maintains that providing information shows respect in health care staff relationships with family members and Bridges et al. (2010) argues that family members can benefit from the provision of honest, easy to understand and comprehensive information. Like previous studies by Bull (2011), van der Veld (2010), Stenwall, Sandberg et al. (2008) and Morita et al. (2007), the findings of this study point to a need to know about delirium as a condition; a need for written and verbal information on causes, manifestations, management, expected course or when their loved one’s absence will end, and consequences. In addition, the findings of this study suggest that family members may benefit from knowing how they can be impacted, how they can cope and, within their preferences, how to help with their older loved one’s care. In addition, some women in this study noticed that their loved one did not acknowledge their episode of delirium or their time in a different reality. Though at times grateful that their loved ones were spared from knowing, advice was needed about sharing what happened during delirium with their loved one and how to cope with the added stress of keeping their absence and the stranger’s presence a secret. Family members may benefit from knowing that some older people may want to forget their episode of delirium, or will be hesitant to discuss their experience (Harding et al., 2008), while others may find recalling their experience helpful, aiding understanding and providing a sense of relief (Andersson, Hallberg, et al., 2002). As family member education leaflets often focus on delirium as a disease and consequent changes to behaviour, there is potential to add
to these resources and include information which addresses the absence, unfamiliarity and loss family members experience during an older loved one’s delirium and provide advice about discussing what happened during delirium. Support resources could also be recommended and detailed.

Delirium leaflets can act as a resource for family members and provide one source of information. Hallberg (2002) suggests that narrative descriptions may be a helpful way to provide information as story based content is easier for family members to understand. For example, insights into what it is like to be a family member during an older loved one’s delirium could be illustrated through family member vignettes. Importantly, education leaflets should not replace empathic communication between health care staff and family members, but can serve as written advice that supports empathic conversations with family members. As Hallberg (2002) argues, educating families is insufficient without an understanding of what it means to each family member to have an older loved one who is acutely confused and the problems faced. It should however, not be left to family members to seek out information. As Laitinen (1993) notes, family members may forego access to information or explanations that are helpful to them as they may be afraid their requests will disturb staff during their work. Despite competing workload demands (Rogers & Gibson, 2002), health care staff should create the space and time to speak with family members and provide information as part of the older person’s care.

Despite the sudden changes that delirium brings to older loved ones, family members often become involved in their loved one’s care, perceiving a need to assist nursing staff to cope with their loved one’s different and often disruptive behaviours, consequent workload increases, safety fears and general ward disruption (Dahlke & Phinney, 2008; Hallberg, 1999; Rogers & Gibson, 2002; Segatore & Adams, 2001). The women in this study visited or stayed with their loved one during delirium, providing emotional support and assisting with their loved one’s care; often calming their loved one, keeping them in their bed or chair, and helping with meals. Though helping with care family members found it difficult to be involved, to know what to do or if what they did was helpful. It is important for health care staff to understand family member preferences for care involvement (Li, 2002), and, rather than assuming participation in care of the older person, negotiating family member involvement so that it does not add to existing family distress or burden (Harding, 2006). In addition, care environments may benefit from adjustment to make it easier for family members to be present (Namba et al., 2007).
Family members who assist with care during delirium may benefit from advice on how to offer emotional support and provide care, including reassurance that they are helping. This includes practical advice on how to cope and help the older person when they are in another reality; when they are aggressive, disoriented, agitated and have hallucinations (van der Velde, 2010). As Stenwall, Johagen et al (2008) suggest, older people may not trust family members when they try to orient them to their reality, so advice should encourage family members to not challenge the reality of the older person; rather to try to understand their perspective and respond to the needs their loved one expresses (Day et al., 2011). Knowing that providing care brings family members into close contact with a person who has become a stranger to family members suggests that health care staff should not make assumptions that family members know how to help their loved one because they are family. Health care staff should respond with compassion and provide reassurance that they can, will and do provide care when family members feel unable to support their older loved one; someone who has become a stranger to them.

Family members in this study said that their knowledge of the older person, even knowledge of past delirium, was not sought nor valued by health care staff. This is consistent with Bridges et al. (2010) who argues that family members are at risk of not having their expertise and contribution to the older person’s care recognised and valued. This draws attention to how family members need meaningful responses from health care staff and need to be respected. During delirium family members may benefit from interventions which help them to feel they are welcome in the care setting, that their knowledge is valued, that their relationships with health care staff will be respectful, that they will be cared for and receive timely help (Bridges et al., 2010). Important to respecting family member’s knowledge of the older person is inviting them to share what they know (Stenwall, Sandberg, et al., 2008), using their knowledge to inform care, as well as respecting family member roles, care limitations and preferences. Taking family members seriously and valuing their expertise may reduce some family member distress. As suggested by Higgins et al. (2007) health care staff need to understand how integral family members are in the care of older people. During an older person’s delirium family members are part of the care team but also have experiences that need to be addressed.

Being with an older loved one during delirium is difficult for family members. They suddenly lose the person they know and are unsure when or if their loved one will again be as they know them. Health care staff, particularly nurses, are ideally placed to respond to family member experiences with compassion and sensitivity; as Bridges et
al (2010) suggests, the actions of health care staff have the potential to make a clear difference to family member experiences and have a central role to play in shaping positive family member relationships. Understanding that family members will likely lose the presence of their familiar loved one and be present with a stranger offers insight into how health care staff can sensitively support family members and respond to their concerns with compassion. However, this raises a question about how well placed health care staff are, particularly nurses, to respond to family members during their loved one's delirium. Research into nurse experiences suggests that nurses find it very challenging to respond during an older person’s delirium and feel impacted themselves (Agar et al., 2012; Hallberg, 1999; Lou & Dai, 2002; McDonnell & Timmins, 2012; Rogers & Gibson, 2002; Schofield et al., 2012). Health care staff may therefore benefit from having their wellbeing issues addressed so they can respectfully and compassionately respond to family members. Addressing wellbeing issues may include, as suggested by Bridges et al. (2010), support through clinical supervision and time to reflect and debrief on their work. It may also require recognition, by health care managers, that older people in delirium, and their family members, require time for compassionate and appropriate care provision. As the women in this study also felt staff did not know how to care for their loved one, ensuring health care staff have access to psychiatric or gerontology trained staff with expertise in delirium care is important. Although all the implications for practice discussed here fall within the scope of practice for health care staff, the feasibility and outcomes of the suggested practices requires future evaluation.

Trustworthiness and Study Limitations

In an attempt to ensure the findings of this study were trustworthy, Guba and Lincoln's (Guba & Lincoln, 1982; Lincoln & Guba, 1985, 1986) criteria for assessing and guiding trustworthiness in qualitative research were used to guide inquiry decisions and activities along with an understanding of phenomenology as a research approach (see Chapter 3: Guiding Approach and Chapter 4: Study Design and Methods). To enable the trustworthiness of the study to be evaluated by others the processes of collecting lived experience descriptions, analysing and interpreting the data and writing a phenomenological narrative have been described and related to the phenomenological approach used in previous chapters. In addition, comment has been made throughout the thesis to provide sufficient details to enable the reader to follow what happened during the study and understand the decisions made. However, in coming to the end of
the study, and to again assess the trustworthiness of this work, some inherent limitations have remained and need to be discussed.

In conducting research guided by existential phenomenology it is necessary to acknowledge that the study is located within the naturalistic paradigm and is an interpretive endeavour. Within this orientation the researcher, no matter how open to their assumptions and aware of their own perspective and position, is not silent in the findings. Rather, they are part of the interpretive process and somewhat within the final interpretation and discussion (Lopez & Willis, 2004). At the same time the women interviewed are situated in the world in their own particular way and express their experience through their own unique perspective (Merleau-Ponty, 1945/2002). Like the researcher, they bring their unique view of living in the world to the study. It is therefore important to acknowledge that the findings from this study have arrived at one interpretation. While valuable in enhancing our understanding of the impact of delirium experiences on family members the findings are, by their nature, particular to the women in the study and this interpretation. They are limited in that the phenomenological perspective holds there remains the possibility of a complimentary or potentially richer description and interpretation of this experience due to the infinite nature of understanding (van Manen, 1990). In addition, the descriptions may be limited as there may be other family member experiences not included in this study which diverge from these descriptions and meanings, such as the experience of male or younger family members. This possible divergence stems from a belief in the uniqueness of each person and their situations; their past, relationships with other people, and their lived world. This is despite evidence from the data that the meanings are shared by the women, and the essence and themes have a universal quality.

Whilst acknowledging the single interpretation evident in the findings of this study, several specific study limitations require consideration. One limitation is the small uncertainty inherent in the way older loved ones were assessed as having delirium. Rather than the more traditional bedside clinical assessment and diagnosis, this study relied largely on accounts from the women and retrospective assessment to ascertain the presence of delirium against standardised diagnostic characteristics for delirium. Difficulties in recruiting participants necessitated a revised recruitment strategy which was no longer located in a clinical context and was unconnected to a current episode of delirium. This approach acknowledged the finely tuned understandings the women had of their older loved one’s usual demeanour, including that during dementia, and when

17 Confusion Assessment Method (CAM). See Chapter 4: Study Design and Methods.
this was suddenly different. In addition to the diagnosis of delirium, a criticism of the study could be the inclusion of family members when their older loved one also had dementia. Though the women clearly articulated a new and sudden change in their older loved one timed with the onset of a precipitating illness, such as a urinary tract infection or pneumonia, it is possible that what the family members experienced was a change related to dementia rather than delirium. It is also possible that living everyday with the changes that have occurred from dementia has sensitised or tempered the way family members experience new changes in their older loved one and what these mean. It remains possible that not all of the women experienced what would be clinically diagnosed as delirium and therefore some experiences described may be similar to, but other than, delirium.

A second limitation of the study is the lack of differentiation in the subtype of delirium experienced by the women. As most family member accounts described characteristics highly suggestive of mixed and hyperactive delirium, the findings of the study cannot be considered to reflect what it is like for family members to experience a specific sub-type of delirium in an older loved one. Given the known differences in behaviour between hypoactive, mixed and hyperactive delirium (see Chapter 1: Study Introduction) it is possible that family members who are with their older loved one during hypoactive, mixed and hyperactive delirium might have different experiences with different meanings.

A third limitation of the study is the lack of diversity in participant gender, cultural backgrounds and relationships. Recruitment of participants was limited to those who could speak English and lived within a two hour drive from the recruitment location. This may have led to the lack of diversity evident in the participant characteristics. Importantly this study only accessed the perspectives of women. As most were daughters, the perspectives of women and that of daughters may be overstated in the findings. Although the gendered nature of the participant group was not surprising, given the higher proportion of female to male carers for older people and people with a disability in the Australian community (Australian Institute of Health and Welfare., 2004), it is important to clearly acknowledge that the experiences of men (e.g. adult sons, husbands, partners or brothers) were not accessed and this may have impacted on the study findings. Moreover this study did not differentiate between the experiences of adult children and those of spouses. It is possible that these specific perspectives could reveal different nuances, perspectives that are not reflected in the study findings. Furthermore participants in this study had Caucasian backgrounds. The perspectives of Aboriginal or Torres Strait Islander (ATSI) peoples and people from different cultural
backgrounds are not reflected in the findings. Because the participant’s experiences were mostly situated in acute hospital wards or residential aged care, the findings presented here may overstate the experience for families who visited their older loved one in these care contexts, and may not fully reflect experiences in other settings, for example, the family home.

A fourth limitation is the variation in the amount of time that had passed since family members experienced an episode of delirium and when they participated in their interviews. Some interviews occurred a long time after the family member’s experience of delirium. While not apparent in their descriptions, the passage of time may have dulled recall of some aspects of the women’s experience or, through reflection and usual social discussion, resulted in recall of an experience that has been reshaped over time. This limitation is, however, tempered by what Morse (2000c) describes as a resurgence of memories and emotions elicited by asking about experiences after the event and a concern in this study with human subjective experiences and responses rather than actual events as viewed objectively. Van Manen (1990) argues that phenomenology is less concerned with the facts or accuracy of the description and more concerned with its plausibility; “whether it is true to our living sense of it” (p. 65).

A fifth limitation of the study stems from the way most women were invited to participate. Accessing participants through a research register provided a group of highly motivated study participants who had participated in different types of research. Though not evident in the data, it is possible that these women provided a particular view of their experience, possibly one which is shaped or filtered in some way by their prior research experiences, or a desire to serve the purpose of being a research register member.

The findings of this study identified absence of an older loved one to be at the core of the women’s experiences during their older loved one’s delirium. Though a clear connection between this finding and the descriptions provided by the women is evident, it needs to be acknowledged that other absences or losses in the women’s lives and the contribution of these losses to the findings has not been described.

A further criticism of the study could be the varied contexts in which participants experienced being with their older loved one during delirium. Some women experienced delirium during residential aged care, others in acute care, at home or in a car. This variation would be of concern if the findings were being generalised, as is the case when using quantitative methodologies, or if the findings claimed the results relate to one particular setting. However, incorporating varied participant settings is consistent
with the phenomenological perspective, one which calls for research to access different appearances of the phenomenon under investigation and to search for the unifying essence (van Manen, 1990).

Despite the limitations and criticisms already discussed, the phenomenological approach, design and the methods employed during the study collected the experiences of female family members and facilitated in-depth consideration of their meaning. The intent of the study was never to generate findings that could be generalised for universal application. Rather, the intent was to explore lived experience so that understanding could be advanced and so inform the support and appropriate inclusion of family members in care. One of the study’s strengths derives from its access to a small group of women, family members who were difficult to access and include in research, and who were able to richly describe their experience. A further strength comes from including family members from different and more diverse backgrounds and contexts than considered in previous work. The trustworthiness and usefulness of this work will ultimately be assessed by the examiners of this thesis and readers of subsequent publications, all of whom will consider whether the meaning of the women’s experience has been captured; whether the descriptions and understandings resonate and elicit the phenomenological nod (Munhall, 2007, p. 562).

**Future Research**

Although there has been increased interest and research into delirium in older people over the past decade, there remains a need for further research which assists health care staff to understand the subjective experiences of family members during their older loved one’s delirium. A more comprehensive understanding is needed which reflects the complexity of their situations and experiences, the impact of these experiences, and the challenges faced. Hence there are many questions still to be answered, some of which are described below.

Revealing absence as a meaning for the experiences of family members in this study has added to our understanding of families and delirium in older people and suggested family member experiences of absence or loss during a loved one’s delirium as a key area for future research. Of particular interest for future research is the nature and variation in the absence or loss experienced by family members, taking into account the sudden onset of delirium, its varied course, the possibility of recurrence and its varied outcomes for older people and their families. This should include an exploration of when absence becomes a problem for family members and the different types of
support that help them to cope. As delirium commonly occurs in conjunction with dementia exploring the similarities and differences in the loss family members experience during delirium and dementia, and when they occur together is also important. An exploration of losses other than the experience of absence is also warranted to consider the cumulative nature of loss and how other losses influence a loved one’s absence during delirium.

As loss of a loved one’s self and grief are linked experiences in current conceptualisations of absence related to chronic changes to health, a concurrent or subsequent avenue for future investigation concerns grief reactions and mourning in family members of older people, particularly during persistent delirium. Grief has been explored in a range of ways in family members who experience the loss of a loved one during ADRD (Boss et al., 1988; Bruce & Schultz, 2001; Doka, 2010; Meuser, Marwit, & Sanders, 2004), suggesting possible initial ways of exploring the experience of family members during an older person’s delirium. Further investigation should enable the identification of loss and grief characteristics for family members during their older loved one’s persistent delirium, and enable consideration of difference or similarity in experience with family members who experience ADRD and absence. Understanding the differences and similarities between grief and loss within the context of delirium has the potential to inform health care interventions that are designed to support family members across various health care settings. As suggested by Meuser et al (2004), researching using a grief perspective may provide a roadmap for assessment and interventions which support for family members, particularly when delirium persists.

The need for family members to understand what is happening to them and to their loved one has been highlighted in this and Stenwall, Sandberg et al.’s (2008) study. Further research should investigate whether educational interventions, such as the one Gagnon et al. (2002) developed for family members of patients with advanced cancer, reduce carer distress in acute care and residential aged care settings during their older loved one’s delirium. The role of education leaflets, with or without information on family member experiences during delirium, should be evaluated.

It is important that future research does not consider family members to be a homogenous group or that their needs during delirium might be the same. Future research should explore and make more visible the experiences of different family members, particularly family members with different roles, genders and relationships to the older person. For example, the differences in the experiences of female spouses and adult daughters, adult sons and adult daughters or male and female spouses need
to be explicated. As current literature reports delirium in older people across varied contexts, including the community, residential aged care and acute care hospitals (Bucht et al., 1999; Cacchione et al., 2003; Folstein et al., 1991), future work should explore the influence of different contexts and models of care on family member experiences during older person delirium. Though the impact of loss during terminal delirium has been explored within the context of palliative care, gravely ill older people in delirium may not be identified as terminally ill nor cared for using palliative care philosophies. Researching in older person health services which provide care underpinned by family, person-centred or palliative models or philosophies of care may uncover different family member experiences to those described in this study and the literature to date. Given the plurality of contexts and situations in which family members encounter an older person during delirium, research which concentrates on particular aspects would be advantageous in understanding contextual nuances and aid the development of support models and context specific interventions for family members.

In future studies improvements should be made to strengthen inclusion criteria for delirium diagnosis in the older person and identification of delirium subtype. Closer proximity in time between data collection and delirium experience may be of benefit, though family distress and bereavement experiences require sensitive attention. The inclusion of different cultural groups and different geographical areas would also be beneficial. The experiences of men and ATSI people are important perspectives which need to be included in future Australian research.

**Conclusion**

Little has been known about the experiences of family members during their older loved one’s delirium, making it difficult for health care staff, in different settings, to understand and respond compassionately to family members. The study described in this thesis emerged from my concern for these family members and an interest in understanding their experiences during delirium. The study findings have revealed that the women who participated in this study experienced existential absence (Sartre, 1943/2003) during their older loved one’s delirium, and found it difficult awaiting the return of their familiar loved one. These findings help to appreciate and understand that the absence of a loved one’s familiar self during delirium is unexpected and distressing for family members. Also, that absence of a loved one’s familiar self is experienced by families in contexts and situations other than loved ones suffering chronic conditions, such as ADRD. Bringing these understandings into play when working with families of older people during delirium has the potential to assist health care staff to respond with
care and compassion, thereby mitigating some of the distress family members experience. Whether or not family members are at home with their loved one or visiting them in residential aged care or acute hospital wards, it is important for health care staff to understand and respond to the experience of family members during this challenging and often difficult time. The study findings also have the potential to increase recognition of family members during the care of the older person, and have highlighted implications for health care practice.

This phenomenological study shows that, despite the complexity of its underpinning philosophical foundations, phenomenology’s ultimate purpose is to extend our understanding of living in a human world. The analysis of the experiences shared by the women in this study has revealed that their experiences were profound; distressingly dominated by the absence of their familiar loved one. It reveals that reaching beyond understandings of delirium as a condition to understand its existential meaning for family members of older people enriches our understanding. Improved understanding offers health care staff the opportunity to better appreciate another person’s point of view, to respond with compassion, provide meaningful support and appropriately include family members in their older loved one’s care. As Cohen et al. (2000) argues, understanding the meaning of experiences for several people provides a sensitive basis upon which a caring relationship can be built.

In summary, it is argued that this study represents an original contribution to the literature on family member experiences during an older loved one’s delirium and adds to the literature on experiences of delirium and delirium in older people more broadly. As few research studies have been published on the experiences of family members during their older loved one’s delirium, this study provides insights which are important for health care staff to consider and take into account during care.

In conclusion, it is hoped that the findings of this study have invited the reader to appreciate what delirium is like for family members; to consider how family members can be appropriately engaged in the care of their older person and supported by health care staff at this difficult time. Often the best we can offer as health care staff is an understanding of the impact of an older person’s condition and its treatment on family member’s so they feel supported, acknowledged as an important part of the older person’s care, and understood as human beings.
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APPENDIX A: REVIEWED LITERATURE
## REVIEWED LITERATURE

### Older People’s Experiences of Delirium

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<thead>
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<th>Title</th>
<th>Methodology / Method</th>
<th>Participants</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Andersson, Hallberg, et al. (2002)</td>
<td>The meaning of acute confusional state from the perspective of elderly patients.</td>
<td>Unstructured interviews Hermeneutic phenomenology (Ricoeur)</td>
<td>n=50 67-96 years</td>
<td>Orthopaedic care Sweden</td>
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<tr>
<td>2 Andersson et al. (1993)</td>
<td>The experience of being confused: A case study</td>
<td>Non-participant observation Interviews Qualitative research</td>
<td>n=1 86 years</td>
<td>Hip Fracture Casualty - General Hospital Sweden</td>
</tr>
<tr>
<td>4 Fagerberg &amp; Jönhagen (2002)</td>
<td>Temporary confusion: A fearful experience.</td>
<td>Interviews Descriptive phenomenology (Giorgi)</td>
<td>n=5 68-90 years</td>
<td>Geriatric clinic Sweden</td>
</tr>
<tr>
<td>5 Sorensen Duppis &amp; Wikblad (2007)</td>
<td>Patients’ experiences of being delirious.</td>
<td>Unstructured interviews Qualitative content analysis Qualitative research</td>
<td>n=15 65 years &amp; over</td>
<td>Orthopaedic care Sweden</td>
</tr>
<tr>
<td>6 Harding et al. (2008)</td>
<td>Dazed and confused: Making sense of delirium after hip fracture.</td>
<td>Semi-structured interviews Qualitative research using IPA</td>
<td>n=9 70-90 years</td>
<td>Orthopaedic trauma wards General hospital Britain</td>
</tr>
<tr>
<td>7 McCurren &amp; Cronin (2003)</td>
<td>Delirium: Elders tell their stories and guide nursing practice.</td>
<td>Semi-structured interviews Descriptive phenomenology</td>
<td>n=14 60 years &amp; over</td>
<td>Medical/surgical wards Acute care hospital America</td>
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<tr>
<td>8 Neville (2008)</td>
<td>Older people with delirium: Worthless and childlike.</td>
<td>Semi-structured interviews Critical gerontology framework Qualitative research</td>
<td>20 sets of data 65-88yrs (mean 75.2 yrs)</td>
<td>Acute care hospital Assessment, treatment and rehabilitation hospital</td>
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<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology / Method</td>
<td>Participants</td>
<td>Setting</td>
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<tr>
<td>Schofield (1997)</td>
<td>A small exploratory study of the reaction of older people to an episode of delirium.</td>
<td>Semi-structured interviews Analysis using constant comparison technique Cross sectional design using grounded theory</td>
<td>n=19 66-91 years</td>
<td>Hospital Britain</td>
</tr>
<tr>
<td>Stenwall, Jönhagen, et al. (2008)</td>
<td>The older patient’s experience of encountering professional carers and close relatives during an acute confusional state: An interview study.</td>
<td>Semi-structured interviews Latent qualitative content analysis Qualitative research</td>
<td>n=7 78-98 years</td>
<td>Geriatric wards x2 Emergency hospital Sweden</td>
</tr>
</tbody>
</table>

**Quantitative**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
<th>Participants</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grover and Shah (2011)</td>
<td>Distress due to delirium experience.</td>
<td>Questionnaire Had delirium</td>
<td>n=53 Delirium n=15 aged 18-83yrs; mean 45.58yrs</td>
<td>Psychiatry</td>
</tr>
</tbody>
</table>

**Literature Reviews**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
<th>Participants</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bélanger &amp; Ducharme(2011)</td>
<td>Patients' and nurses' experiences of delirium: A review of qualitative studies.</td>
<td>Qualitative studies n=9; literature reviews n=1 (O’Malley et al., 2008) (not all older people)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>O’Malley et al.(2008)</td>
<td>The delirium experience: A review.</td>
<td>Qualitative studies n=8 (not all older people)</td>
<td></td>
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</table>

**Self Report**

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<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
<th>Participants</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crammer (2002)</td>
<td>Subjective experience of a confusional state</td>
<td>Self report by psychiatrist Aged 79years Admitted to hospital with chronic renal failure and a history of atrial fibrillation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Nurses/Health Care Staff Experiences During Older Person Delirium

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
<th>Participants</th>
<th>Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Andersson et al. (1993)</td>
<td>The experience of being confused: A case study.</td>
<td>Non-participant observation Interviews Ricoeur – naïve reading and structural analysis Qualitative research</td>
<td>n=3 nurses</td>
<td>Casualty – Hip Fracture General Hospital Sweden</td>
</tr>
<tr>
<td>2 Andersson et al. (2003)</td>
<td>Nurses’ experiences of the encounter with elderly patients in acute confusional state in orthopaedic care.</td>
<td>Unstructured interviews Latent content analysis Qualitative research</td>
<td>n=48 Registered nurses n=26 Licensed practical nurses n=22</td>
<td>Orthopaedic Unit Acute Hospital Sweden</td>
</tr>
<tr>
<td>3 Agar et al. (2012)</td>
<td>Making decisions about delirium: A qualitative comparison of decision making between nurses working in palliative care, aged care, aged care psychiatry, and oncology.</td>
<td>Semi-structures interviews Thematic content analysis Qualitative research using a grounded theory perspective</td>
<td>n=40 nurses</td>
<td>Palliative care Oncology Aged care Aged Psychiatry Australia</td>
</tr>
<tr>
<td>4 Dahlke &amp; Phinney (2008)</td>
<td>Caring for hospitalised older adults at risk for delirium: The silent, unspoken piece of nursing practice.</td>
<td>Interviews Qualitative research</td>
<td>n=12 Registered nurses 32-61 years (mean 48 yrs)</td>
<td>Medical &amp; surgical units Acute Hospital Canada</td>
</tr>
<tr>
<td>5 Lou &amp; Dai (2002)</td>
<td>Nurses' experience of caring for delirious patients.</td>
<td>In-depth interviews Grounded theory NOTE theoretical saturation not reached</td>
<td>n=4 Graduate nursing students</td>
<td>Medical &amp; Surgical units Acute Hospital Thailan</td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology / Method</td>
<td>Participants</td>
<td>Setting</td>
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</tr>
<tr>
<td>Neville (2006)</td>
<td>Delirium and older people: Repositioning nursing care.</td>
<td>20 sets of data in total Discourse analysis</td>
<td>n=2 Registered nurses &amp; n=1 Hospital doctor Specialist Delirium Service</td>
<td>Acute care hospital Assessment, treatment and rehabilitation hospital New Zealand</td>
</tr>
<tr>
<td>Rogers &amp; Gibson (2002)</td>
<td>Experiences of orthopaedic nurses caring for elderly patients with acute confusion.</td>
<td>Semi-structures interviews Qualitative research</td>
<td>n=10 Registered nurses</td>
<td>Orthopaedic unit Tertiary Care Hospital Canada</td>
</tr>
<tr>
<td>Schofield et al. (2012)</td>
<td>How nurses understand and care for older people with delirium in the acute hospital: A critical discourse analysis.</td>
<td>Interviews Participant observation Discourse analysis</td>
<td>n=15 Registered nurses</td>
<td>Acute care wards Acute Hospital Britian</td>
</tr>
<tr>
<td>Stenwall et al. (2007)</td>
<td>Encountering the older confused patient: Professional carers' experiences.</td>
<td>Interviews Descriptive phenomenology</td>
<td>n=10 nurses (RNs and ANs)</td>
<td>Geriatric ward specialising in care of confused older people Metropolitan Hospital Sweden</td>
</tr>
</tbody>
</table>

**Quantitative Research**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
<th>Participants</th>
<th>Setting</th>
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</thead>
<tbody>
<tr>
<td>McDonnell &amp; Timmins (2012)</td>
<td>A quantitative exploration of the subjective burden experienced by nurses when caring for patients with delirium.</td>
<td>Quantitative descriptive Self reporting Strain of Care for Delirium Index Questionnaire</td>
<td>Random sample=800 Response=181 Response rate 22.62% nurses</td>
<td>National nurses register Includes nurses working in paediatrics and community. Ireland</td>
</tr>
<tr>
<td>Milisen et al. (2004)</td>
<td>The Strain of Care for Delirium Index: A new instrument to assess nurses' strain in caring for patients with delirium.</td>
<td>Expert panel strain index tool review Strain of Care for Delirium Index Questionnaire</td>
<td>n=190 nurses</td>
<td>University hospitals Dutch</td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology / Method</td>
<td>Participants</td>
<td>Setting</td>
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<tr>
<td><strong>Literature Reviews</strong></td>
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</tr>
<tr>
<td>1. Bélanger &amp; Ducharme (2011)</td>
<td>Patients’ and nurses’ experiences of delirium: A review of qualitative studies.</td>
<td>Qualitative studies n=6 (all nurses) (not all older people)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. O’Malley et al. (2008)</td>
<td>The delirium experience: A review.</td>
<td>Professional carer studies n=3 (all nurses) (not all older people)</td>
<td></td>
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<tr>
<td><strong>Discussion Chapters</strong></td>
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# Family Members’ Experiences During Older Person Delirium

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<tr>
<th>Authors</th>
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<tbody>
<tr>
<td><strong>Qualitative Research</strong></td>
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<tr>
<td><strong>Quantitative Research</strong></td>
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</tr>
<tr>
<td>1</td>
<td>Bull (2011)</td>
<td>Delirium in older adults attending adult day care and family caregiver distress.</td>
<td>Interview questionnaires-Carer’s assessment of managing index, symptom distress questionnaire, and family caregiver distress questionnaire</td>
<td>n=30 Family/carers</td>
</tr>
<tr>
<td><strong>Literature Reviews</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1</td>
<td>O’Malley et al. (2008)</td>
<td>The delirium experience: A review.</td>
<td>Family studies n=1 (Breitbart) (not focused on older people)</td>
<td></td>
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<tr>
<td><strong>Discussion Chapter</strong></td>
<td></td>
<td></td>
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<tr>
<td>1</td>
<td>Hallberg (2002)</td>
<td>The role of families, family caregivers, and nurses.</td>
<td>Discussion chapter</td>
<td></td>
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</tbody>
</table>
### Family Member Experiences During Delirium in Palliative / Advanced Cancer Care (not older person focused)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
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<th>Setting</th>
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<tr>
<td><strong>Qualitative Research</strong></td>
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</tr>
<tr>
<td>1 Brajtman (2003)</td>
<td>The impact on the family of terminal restlessness and its management.</td>
<td>Phenomenology</td>
<td>n=20 Family</td>
<td>Terminal Canada</td>
</tr>
<tr>
<td>2 Brajtman (2005)</td>
<td>Helping the family through the experience of terminal restlessness.</td>
<td>Interviews</td>
<td>n=20 Family</td>
<td>Terminal Canada</td>
</tr>
<tr>
<td>3 Cohen &amp; Pace (2009)</td>
<td>Delirium in advanced cancer leading to distress in patients and family caregivers.</td>
<td>Phenomenology</td>
<td>n=37 Family</td>
<td>Advanced Cancer America</td>
</tr>
<tr>
<td>4 Greaves et al. (2008)</td>
<td>Family caregivers' perceptions and experiences of delirium in patients with advanced cancer.</td>
<td>Semi-structured interviews</td>
<td>n=10 Family</td>
<td>Advanced Cancer Australia</td>
</tr>
<tr>
<td>5 Namba et al. (2007)</td>
<td>Terminal delirium: Families' experience.</td>
<td>Interviews</td>
<td>n=20 Family</td>
<td>Terminal cancer Japan</td>
</tr>
<tr>
<td><strong>Quantitative Research</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>1 Breitbart et al. (2002)</td>
<td>The delirium experience: Delirium recall and delirium-related distress in hospitalised patients with cancer, their spouses/caregivers, and their nurses</td>
<td>Delirium experience questionnaire</td>
<td>n=75 Cancer Americia</td>
<td></td>
</tr>
<tr>
<td>2 Buss et al. (2007)</td>
<td>Associations between caregiver-perceived delirium in patients with cancer and generalized anxiety in their caregivers.</td>
<td>SCARED tool</td>
<td>n=200 Terminal cancer America</td>
<td></td>
</tr>
<tr>
<td>4 Morita et al. (2007)</td>
<td>Terminal delirium: Recommendations from bereaved families' experiences</td>
<td>Questionnaire</td>
<td>n=242 Bereaved Response rate 72% Japan</td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology / Method</td>
<td>Participants</td>
<td>Setting</td>
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</tr>
<tr>
<td>5 Morita et al. (2004)</td>
<td>Family-perceived distress from delirium-related symptoms of terminally ill cancer patients.</td>
<td>Questionnaire Pt. mean age 67yrs</td>
<td>n=195 Bereaved Response rate 65%</td>
<td>Terminally ill Japan</td>
</tr>
</tbody>
</table>

**Literature Reviews**

<table>
<thead>
<tr>
<th>Authors</th>
<th>Title</th>
<th>Methodology / Method</th>
</tr>
</thead>
</table>
APPENDIX B: INTERMEDIARY RECRUITMENT

INFORMATION PACK

1. Ward Poster
2. Recruitment Information for NUMs/CNCs
3. Study Inclusion Criteria
4. Confusion Assessment Method
5. Participant Study Information and Invitation
6. Participant Consent
Family Research Study

Have you visited an older member of your family on this ward?

Have they **suddenly** become confused?

Would you like to talk about your experiences?

Family members who have visited an older person who has suddenly or unexpectedly become confused are invited to talk to me about their experiences.

You may be able to participate in this study if:

- You have visited your older family member at least twice when the older person was confused, and
- You are willing to be interviewed by the researcher.

*If you would like to receive more study information please ask to speak to the Nursing Unit Manager for this ward*

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 1006/155.05.
Recruitment Information for NUMs/CNCs  
(Version 4, 23/02/2011)

**Introduction to the study**

The purpose of this research is to explore what it is like for family members to visit a hospitalised older person when the older person has an episode of acute confusion, with or without a pre-existing chronic confusion associated with dementia or Alzheimer's disease. It plans to uncover the meaning of this experience for family members themselves, rather than healthcare professionals or older people, so their experience can be understood by healthcare staff who are responsible for family support and involvement in care during hospitalisation of the older person. The study is a qualitative study guided by phenomenology and will involve family members participating in face-to-face interviews with the researcher on at least one occasion.

The recruitment settings for the study are three wards and their outlier patients (J3, F1, and H2) and older people assessed by the Psychiatric Liaison Team at the JHH. The recruitment process plans to involve you (NUMs/CNCs) in identifying potential family member participants and providing initial information about the study. After introducing the study to family members there is no further involvement in the study.

**Delirium**

Delirium is an acute type of confusion that may or may not be superimposed on chronic confusion (e.g. dementia or Alzheimer’s disease). In older people delirium with pre-existing dementia is common and often results in a sudden or acute change in the older person’s usual behaviour and level of confusion. Like all delirium, it is a sign of severe illness and vulnerability.

The main acute clinical features of delirium include:

- A disturbance of consciousness (i.e. reduced clarity of awareness of the environment) with reduced ability to focus, sustain or shift attention.
- A change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a pre-existing or evolving dementia.
- A disturbance that develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.
- Evidence from the history, physical examination, or laboratory findings that the disturbance is caused by the direct physiological consequences of a general medical condition, substance intoxication or substance withdrawal.  
  (American Psychiatric Association, 1994,p.4)

Delirium can be distinguished from dementia in clinical practice by the following clinical features and through the use of the CAMI and MMSE assessment tools:
<table>
<thead>
<tr>
<th></th>
<th>Delirium</th>
<th>Dementia</th>
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</thead>
<tbody>
<tr>
<td><strong>Onset</strong></td>
<td>Acute or subacute</td>
<td>Insidious or chronic</td>
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<tr>
<td><strong>Course</strong></td>
<td>Fluctuating throughout a day, usually revolves over days to weeks</td>
<td>Progressive</td>
</tr>
<tr>
<td><strong>Conscious level</strong></td>
<td>Often impaired, can fluctuate rapidly, decreased levels of awareness/attentiveness</td>
<td>Alert, clear levels of attention until later stages</td>
</tr>
<tr>
<td><strong>Cognitive defects</strong></td>
<td>Poor short term memory, poor attention span</td>
<td>Poor short term memory, attention less affected until severe</td>
</tr>
<tr>
<td><strong>Hallucinations</strong></td>
<td>Common, especially visual</td>
<td>Often absent</td>
</tr>
<tr>
<td><strong>Delusions</strong></td>
<td>Fleeting, non-systematised</td>
<td>Often absent</td>
</tr>
<tr>
<td><strong>Psychomotor activity</strong></td>
<td>Increased, reduced, or unpredictable</td>
<td>Can be normal</td>
</tr>
</tbody>
</table>

(Brown & Boyle, 2009)

**Before contact with potential participants**

Before recruitment commences I will arrange a briefing session with you to provide information/answer questions about the study and discuss;

1. ethical issues in approaching potential participants,
2. study inclusion criteria,
3. commencement date for recruitment,
4. who to contact with recruitment questions/problems and how,
5. non-disclosure of patient and family member details.

At this meeting I will provide you with *Participant Study Information Packs* (adult, minors and large print) and this *Recruiters Information Pack*.

**How family members will be invited to participate in the study**

Family members will be invited to participate in two ways;

1. **via an approach by the NUM/CNC from a participating ward (H2, F1, J3) or team,**
2. **via information from Study Information Posters displayed in each participating ward,** or
3. **via an approach from the CNC Dementia/Delirium Acute Care after being identified through the Psychiatric Liaison Team consultation report**

An important initial step in the recruitment of family members is confirmation that the older person being visited has delirium and meets other inclusion criteria (see inclusion criteria checklist attached). NUMs/CNCs are requested to confirm that the older person meets all the inclusion criteria. This will include checking existing notations in the older person’s medical record for a diagnosis of delirium or completing a CAMI assessment – form no.HNEMR52. The results of the CAMI assessment are to be recorded on the CAMI form and placed in the older person’s medical record.
Before you approach a family member about the study please consider the family member inclusion criteria (see inclusion criteria checklist attached). Then when you approach a family member please:

- broadly inform the family member about the study,
- ask the family member if they might be interested in being involved in the study,
- provide interested family members with a Participant Study Information Pack suited to their age,
- request contact with the student researcher to ask questions or express concerns (detailed in the pack), and
- request family members return a completed consent form to me if they wish to accept the invitation to participate (using the supplied reply paid and addressed envelope).

Consent forms in the study information pack will be numbered so I can identify how many information packs are distributed, how many completed consent forms are returned and how many family members become participants in the study.

**Guidelines for contact with potential participants**

In approaching and/or discussing the study with family members please;

1. be sensitive to family member and older person concerns about experiencing delirium, family member knowledge of the older person’s condition, distress levels, the older person’s privacy and family member age,
2. take care in how you approach family members to prevent family members from feeling obligated or pressured to participate (they may think that care of the older person is dependent on accepting the invitation to be in the study),
3. reassure family members that participation is completely voluntary and unconnected to the care of their older person, and that staff on the ward will not know they are participating,
4. provide interested family members with a Participant Study Information Pack containing a study information statement and invitation, consent form, and reply paid envelop,
5. refrain from keeping or giving details about the older person who has delirium or family members approached or provided with a study information pack to the student researcher,
6. advise family members to contact the student researcher with questions about the study and, should they wish to participate, invited family members to complete the consent form and return it to the student researcher using the supplied reply paid envelope.
7. decline requests to take completed consent forms and suggest that the family member take time to consider the invitation, ask questions with the student researcher and, when sure, to return the completed consent form via the supplied reply paid envelope.

**Questions of concerns about your involvement?**

I welcome contact from you about any concerns or questions you have related to the study. My contact details are listed below. If you cannot contact me or if you would prefer to speak to one of my supervisors their contact details are;
Thankyou

I would like to thank you for the support you have provide me in developing my study and for your commitment and involvement in the recruitment of family members. I really appreciate the time you are giving and the expertise you are contributing to my study.

Jenny Day
PhD Candidate
School of Nursing and Midwifery
The University of Newcastle
Ph: 492 12091 (Monday and Tuesday)
Mobile: 0412 639 518
Email: Jenny.day@newcastle.edu.au

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 10/06/16/5.05.
Study Inclusion Criteria
(version 3, 23/02/2011)

**Step 1**
OLDER PERSON INCLUSION CRITERIA

For this study the older person visited by the family member needs to meet all of the following criteria before family members are given a Participant Study Information Pack:

- be admitted to J3, F1, H2 OR be an outlier patient of the medical/surgical team of F1 or J3, OR be assessed by the JHH Psychiatric Liaison Team,
- cared for in an acute hospital ward other than an emergency department, intensive care, coronary care, burns or a high dependency unit,
- diagnosed with delirium in the medical record or have positive scores for 1 and 2, AND EITHER 3 or 4 in a CAMI assessment,
- have no history of acute brain injury, terminal illness, cerebral infarction or psychiatric diagnosis,

AND

- aged 65 years or over.

**Step 2**
FAMILY MEMBER CRITERIA

For this study family members should be considered if the older person has met all the criteria above and the family member meets the following criteria.

- views themselves as a family member of the older person, (does not have to be a blood or close relative, nor legally related. May be a carer.)
- has visited the older person whilst the older person is in delirium on at least two occasions,
- is able to communicate in English,
- is able to give an informed consent to participate in the study,
- is willing to meet with the researcher on at least one occasion to be interviewed.

AND

- is willing to be interviewed at a location within 2 hours drive of the JHH.
THE CONFUSION ASSESSMENT METHOD INSTRUMENT (CAMI)

Feature 1. Acute onset and fluctuating course
This feature is usually obtained from a family member or carer and is shown by positive responses to the following questions:
Is there evidence of an acute change in mental status from the patient's baseline?
Did the (abnormal) behaviour fluctuate during the day, that is, tend to come and go, or increase and decrease in severity? Yes ☐ No ☐

Feature 2. Inattention
This feature is shown by a positive response to the following question:
Did the patient have difficulty focusing attention, for example, being easily distractible, or having difficulty keeping track of what is being said? Yes ☐ No ☐

Feature 3. Disorganised thinking
This feature is shown by a positive response to the following question:
Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject? Yes ☐ No ☐

Feature 4. Altered level of consciousness
This feature is shown by an answer other than "alert" to the following question:
Overall, how would you rate this patient's level of consciousness?
☐ Alert [normal]
☐ Vigilant [hyperalert]
☐ Lethargic [drowsy, easily aroused]
☐ Stupor [difficult to arouse]
☐ Coma [unarousing]

The diagnosis of delirium requires the presence of:
Features 1 and 2 and Either Feature 3 or Feature 4
☐ 1 ☐ 2 ☐ 3 ☐ 4

If delirium indicated notify Medical Officer as soon as possible and document finding and referral details in the clinical notes.

Sign: ____________________________ Print Name: ____________________________

Designation: ____________________________ Date: ____________________________

Research Project: Family experiences-visiting an older person who has acute confusion

(Version 2, 21/06/2010)

You are invited to take part in the research project identified above. This research is being conducted by Jenny Day. Jenny is from the School of Nursing & Midwifery at The University of Newcastle and this research is for her PhD studies. It is being supervised by Professor Isabel Higgins and Professor Diana Keatinge who are also from the School of Nursing & Midwifery at The University of Newcastle.

Why the research being done

The purpose of this research is to explore what it is like for family members to visit a hospitalised older person when the older person has acute confusion. Acute confusion is when the older person has a sudden or unexpected change in how they behave, often becoming inattentive, confused or agitated. They may also seem unmotivated or more withdrawn and unaware than usual. They may talk about visual images that you can’t see, be more difficult to reason with, or want to walk without reason. These changes develop suddenly and may also come and go. Their behaviour is suddenly different to how they usually are.

It is hoped that understanding what this experience is like for family members will help hospital staff to provide better family member support in the future.

Who can participate in the research?

You are invited to participate in this research because you have recently visited an older person in an acute state of confusion in hospital.

This study is suitable for you if:

- The family member you visited in hospital was aged 65 years or more,
- You are a family member to the older person (family members are those people who feel they are part of the older person’s family – you do not have to be a blood relative, be married to or live with the older person),
- You have visited the older person at least twice when they were acutely confused,
- You can communicate in English,
- You are willing to meet with the researcher on at least one occasion to be interviewed, and
- You willing to be interviewed at a location within 2 hours drive of the John Hunter Hospital.
**Your choice about participating**

Participation in this research is entirely your choice. Only those family members who give their voluntary informed consent will be included in the research. Whether you decide to participate or not, your decision will not disadvantage you in any way and will not affect the hospital care of your older family member. Your decision to participate or refuse will not be disclosed by the researcher to hospital staff, the hospital or other family members.

If you do decide to participate, you may change your mind and withdraw from the research at any time without giving a reason and without any consequence to you or your older family member. You also have the option of withdrawing your information without giving a reason.

If the researcher believes that participating in this research is upsetting to you, she will discuss this with you and may suggest you withdraw from the research.

**What you will be asked to do and how much time it will take**

If you agree to participate, you will be asked to meet with the researcher to be interviewed on at least one occasion. Interviews should last about one hour and will be held in a place and at a time agreeable to you. During the interview you will be asked to talk about what visiting your acutely confused older family member in hospital was like. After your first interview you may be asked for follow-up interviews to clarify or provide more detail about your experience. Participation in these interviews is voluntary. With your consent each interview will be digitally recorded and then typed verbatim into a word document by a paid transcriber or the researcher. During the interview you can ask for the digital recorder to be stopped or for your recording to be erased.

After each interview you will be asked to read the typed version of your interview and to meet or discuss with the researcher any changes that you would like made. These discussions or meetings may vary in length but should not last more than 45 minutes. Participation in this part of the research is voluntary and will be at a time and venue that is agreeable to you.

You will also be asked to comment on a summary of the final findings of the research. Participation in this part of the research is also voluntary. All contact with you about your involvement in the research will be made by the researcher, or the research supervisors, Professor Isabel Higgins or Professor Diana Keatinge. There will be no reimbursement or payment to participants for involvement in this research.

**The risks and benefits of participating**

I cannot promise you any benefit from participating in this research. It is possible that you may find the opportunity to talk about your experience to be of benefit. You may also find participation unpleasant or distressing. If you do experience any distress as a result of participation in this research please contact me and we can discuss how to access counselling or other support services.

**Protection of your privacy**

Any information collected by the researcher which might identify you will be stored securely and only accessed by the researcher and research supervisors named above, unless you consent otherwise or except as required by law. If you disclose specific details about an illegal incident (eg date, place, perpetrators) during the research, the researcher may be obliged to report the information to the Police or other authority without your consent.

Interview data will be de-identified by replacing identifying details with pseudonyms and will be stored separately to identifying data. Transcribers used to produce the typed version of your interview will be required to sign a confidentiality and data security/retention undertaking.
All publications and presentations related to this research will use de-identified information and data, including the summary of results provided to participants at the end of the study.

Data from this research will be retained for at least 5 years after completion of the research in a secure cabinet at the School of Nursing and Midwifery, The University of Newcastle. Data from this research will then be destroyed in accordance with The University of Newcastle Research Data and Materials Management policy and procedure. Due care will be taken to ensure that disposal is secure and takes account of the confidential nature and possible sensitivity of the data.

**How will the information collected be used?**
The data collected in this research will be reported in a thesis to be submitted for my degree, in papers in professional journals and at professional conferences or seminars. These reports may contain words said by you during an interview however you will not be identified by name. If you would like to receive a copy of a publication please contact the researcher using the contact details below.

**Complaints about this research**
This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 10/06/16/5.05 and The University of Newcastle Human Research Ethics Committee, Reference H-2010-1178. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager Research Ethics and Governance, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, Email: Hnehrec@hnehealth.nsw.gov.au.

**What you need to do to participate**
Please read this *Study Information Statement & Invitation* and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact me. My contact details are detailed below.

If you would like to participate, please complete the attached consent form and return it to me in the reply paid envelope provided. Return of a completed consent form will be taken as your informed and voluntary consent to participate. When I receive your consent form I will contact you to discuss the research, answer any questions you may have and to arrange a convenient interview time and location.

Please keep this *Study Information Statement & Invitation* and the spare copy of the consent form for your future reference.

**Further information and questions?**
If you would like further information or have questions about the research please contact the researcher using the following contact details;

Jenny Day  Phone: 4921 2091  email: jenny.day@newcastle.edu.au

Thank you for considering this invitation to participate in my research.
Researcher

Jenny Day
PhD Candidate

Research Supervisors:

Dr Isabel Higgins
Professor Older Person Care

Dr Diana Keatinge
Professor Paediatric, Youth & Family Health Nursing
Study Information Statement & Invitation
Family Member 13 to 18 Years of Age

Research Project: Family experiences-visiting an older person who has acute confusion
(Version 2, 21/06/2010)

You are invited to take part in the family research project named above. This research is being done by Jenny Day. Jenny is from the School of Nursing & Midwifery at The University of Newcastle and this research is for her PhD studies. It is being supervised by Professor Isabel Higgins and Professor Diana Keatinge who are also from the School of Nursing & Midwifery at The University of Newcastle.

Why the research being done
The purpose of this research is to explore what it is like for family members to visit a hospitalised older person when the older person has acute confusion. Acute confusion is when the older person has a sudden or unexpected change in how they behave, often becoming less attentive, muddled or restless. They may also seem unmotivated or more withdrawn and unaware than usual. They may talk about things that you can’t see, be more difficult to reason with, or want to walk without reason. These changes develop suddenly and may also come and go. Their behaviour is suddenly different to how they usually are.

It is hoped that understanding what this experience is like for family members will help hospital staff to provide better family member support in the future.

Who can participate in the research?
You are invited to participate in this research because you have recently visited an older person in an acute state of confusion in hospital.
This study is suitable for you if:

- The family member you visited in hospital was aged 65 years or more,
- You are a family member to the older person (family members are those people who feel they are part of the older person’s family – you do not have to be a blood relative or live with the older person),
- You have visited the older person at least twice when they were acutely confused,
- You can communicate in English,
- You are willing to meet with the researcher on at least one occasion to be interviewed, and
You willing to be interviewed at a location within 2 hours drive of the John Hunter Hospital.

Your choice about participating
Participation in this research is entirely your choice. Only family members who give their voluntary informed consent will be included in the research. As a person aged less than 18 years of age, you will also need the consent of a parent, guardian or primary caregiver. Whether you decide to participate or not, your decision will not disadvantage you in any way and will not affect the hospital care of your older family member. Your decision to participate or refuse will not be disclosed by the researcher to hospital staff, the hospital or other family members.
If you do decide to participate, you may change your mind and leave the research at any time without giving a reason and without any consequence to you or your older family member. You also have the option of withdrawing your information without giving a reason.
If the researcher believes that participating in this research is upsetting to you, she will discuss this with you and may suggest you withdraw from the research.

What you will be asked to do and how much time it will take
If you agree to participate, you will be asked to meet with the researcher to be interviewed on at least one occasion. Interviews should last about one hour and will be held in a place and at a time agreeable to you. You may choose to bring a support person with you to the interview or you may be interviewed with other family members participating in the research. During the interview you will be asked to talk about what visiting your acutely confused older family member in hospital was like. After your first interview you may be asked for follow-up interviews to clarify or provide more detail about your experience. Participation in these interviews is voluntary. With your consent each interview will be digitally recorded and then typed word for word into a typed document by a paid transcriber or the researcher. During the interview you can ask for the digital recorder to be stopped or for your recording to be erased.
After each interview you will be asked to read the typed version of your interview and to meet or discuss with the researcher any changes that you would like made. These discussions or meetings may vary in length but should not last more than 45 minutes. Participation in this part of the study is voluntary and will be at a time and venue that is agreeable to you.
You will also be asked to comment on a summary of the final findings of the research. Participation in this part of the study is also voluntary.
All contact with you about your involvement in the research will be made by the researcher or the research supervisors Professor Isabel Higgins or Professor Diana Keatinge. There will be no reimbursement or payment to participants for involvement in this research.

The risks and benefits of participating
I cannot promise you any benefit from participating in this research. It is possible that you may find the chance to talk about your experience to be of benefit. You may also find participation unpleasant or distressing. If you do experience any distress as a result of participation in this study please contact me and we can discuss how to access counseling or other support services.

Protection of your privacy
Any information collected by the researcher which might identify you will be stored securely and only accessed by the researcher or research supervisors named above, unless you consent otherwise or except as required by law. If you disclose specific details about an illegal incident (e.g. date, place, perpetrators) during the research, I
may be obliged to report the information to the Police or other authority without your consent.

Interview data will have details which identify you replaced with pseudonyms and de-identified information will be stored separately to identifying information. Transcribers used to produce the typed version of your interview will be required to sign a confidentiality and data security/retention undertaking.

All publications and presentations related to this research will use de-identified information and data, including the summary of results provided to participants at the end of the study.

Data from this research will be retained for at least 5 years after completion of the research in a secure cabinet at the School of Nursing and Midwifery, The University of Newcastle. Data from this research will then be destroyed in accordance with The University of Newcastle Research Data and Materials Management policy procedure. Due care will be taken to ensure that disposal is secure and takes account of the confidential nature and possible sensitivity of the data.

**How will the information collected be used?**

The data collected in this research will be reported in a thesis to be submitted for my degree, in papers in professional journals and at professional conferences or seminars. These reports may contain words said by you during an interview however you will not be identified by name. If you would like to receive a copy of a publication please contact the researcher using the contact details below.

**Complaints about this research**

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 10/06/16/5.05 and The University of Newcastle Human Research Ethics Committee, Reference H-2010-1178. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager Research Ethics and Governance, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, Email: Hnehrec@hnehealth.nsw.gov.au.

**What you need to do to participate**

Please read this *Study Information Statement & Invitation* and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact me. My contact details are detailed below. Please ask your parent/guardian or primary carer to also read this *Study Information Statement & Invitation* and to contact me if they have any questions. Please discuss your participation with them before making your final decision. If you consent to participating in this research, the consent of your parent/guardian or primary carer is also needed. If your parent/guardian or primary carer consents to you participating in this research the final decision will rest with you.

If you would like to participate, please complete the attached consent form and return it to the researcher in the reply paid envelope provided. Return of a completed consent form will be taken as your informed and voluntary consent to participate. When I receive your consent form I will contact you to discuss the research, answer any questions you may have and to arrange a convenient interview time and location.

Please keep this *Research Information Statement* and the spare copy of the consent form for your future reference.
Further information and questions?
If you would like further information or have questions about the research please contact the researcher using the following contact details;

Jenny Day  Phone: 4921 2091  email: jenny.day@newcastle.edu.au

Thank you for considering this invitation to participate in my study.

Researcher

Jenny Day
PhD Candidate

Research Supervisors:
Dr Isabel Higgins  Dr Diana Keatinge
Professor Older Person Care  Professor Paediatric, Youth & Family Health Nursing
Participant Consent Form
Adult Family Member

Consent Statement
I agree to participate in the research project named above and give my consent voluntarily.

I understand that the project will be conducted as described in the Study Information Statement & Invitation, a copy of which I have read and retained. I have had the opportunity to have questions answered to my satisfaction.

I understand I can withdraw from the research project at any time and do not have to give any reason for withdrawing.

I understand that my personal information will remain confidential to the researchers, except as required by law, and that publication resulting from this research will use de-identified data.

I consent to
• participating in one or more interviews and having my interviews recorded and transcribed into a typed version by a paid transcriber or the researcher.

I also consent to (please circle yes or no for each item);
Yes / No checking the content of typed versions of my interviews;
Yes / No commenting on a summary of the final results of the study.

Name (please print):_____________________________________________________
Signature:____________________________________________________________ 
Date:______________________________________________________________
Contact Details: Phone________________________________ Email / Mobile phone __________________
Address __________________________________________________________________
Age:_____________________ Place of birth:______________________________
Relationship to the older person visited at the John Hunter Hospital:
________________________________________________________________________

Research Project: Family experiences-visiting an older person who has acute confusion
(Version 1, 22/05/2010)

Professor Isabel Higgins, and
Professor Diana Keatinge
School of Nursing and Midwifery
Faculty of Health
The University of Newcastle
University Drive
Callaghan, NSW, 2308
Ph. 4921 6304 Fax. 4921 6301
Isabel.higgins@newcastle.edu.au
Diana.keatinge@newcastle.edu.au
Participant Consent Form
Family Member 13 to 18 Years of Age

Consent Statement (Family members 13 to 18 years of age)
I agree to participate in the research project named above and give my consent voluntarily.

I understand that the research project will be conducted as described in the Study Information Statement & Invitation, a copy of which I have read and retained. I have had the opportunity to have questions answered to my satisfaction and I have discussed my involvement with my parent / guardian or primary carer.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I understand that my personal information will remain confidential to the researchers, except as required by law, and that publication resulting from this research will use de-identified data.

I consent to
- participating in one or more interviews and having my interviews recorded and transcribed into a typed version by a paid transcriber or the researcher.

I also consent to (please circle yes or no for each item);

Yes / No checking the content of typed versions of my interviews;

Yes / No commenting on a summary of the final results of the study.

Name (please print):________________________________________________________

Signature:________________________________________ Date:_______________________

Contact Details: Phone________________________ Email / Mobile phone ______________

Address ________________________________________________________________________

Age:__________________________ Place of birth:

_____________________________________________________________________________

Relationship to the older person visited at the John Hunter Hospital:

______________________________________________

Parent/Guardian/Primary Carer:

Name:________________________________________ Signature__________________________
APPENDIX C: RESEARCH REGISTER RECRUITMENT INFORMATION

1. Sample HMRI Letter of Invitation
2. Participant Study Information and Invitation
3. Participant Consent
30 August 2017

Dear [First Name],

Thank you for your continued membership of the HMRI Research Register. Below is a letter inviting you to participate in a research study. The invited experience of family members who are either personally with an older person with an older person have been conducted by Dr. [Name], a professor of psychology and clinical psychology at the University of Newcastle.

The purpose of the study is to obtain a general description of the research and describe the organisation of the procedures involved in participating in the study. The research will also include the assessment of your personal and family medical history and any benefits or consequences that may result from your participation.

The research has been independently reviewed and approved by the Human Research Ethics Committee and the Human Research Ethics Committee as being of significant scientific value and as satisfying the National Statement on Ethical Conduct in Research Involving Humans (NHMRC, 1992).

Participation in studies associated with the HMRI Research Register is voluntary and you are always free to withdraw from any study at any stage.

If you are interested in participating in this study, please fill out the attached application form and return it to us at your earliest convenience. We will forward your contact information to the researchers listed above, who will contact you with further details.

If you have any questions or concerns, please contact us on 9865 5333 and we will be happy to provide you with any further information.

Thank you for taking the time to consider this invitation, and we look forward to receiving your response.

Warm regards,

[Name], Coordinator, HMRI Research Register

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In partnership with our community
Family experiences – being with, or caring for, an older person who has acute confusion

You are invited to take part in the research project identified above. This research is being conducted by Jenny Day. Jenny is from the School of Nursing & Midwifery at The University of Newcastle and this research is for her PhD studies. The research is being supervised by Professor Isabel Higgins and Professor Diana Keatinge who are also from the School of Nursing & Midwifery at The University of Newcastle.

Why the research being done
The purpose of this research is to explore what it is like for family members to be with or care for an older person when the older person has delirium. Delirium is also known as acute confusion and is when the older person has a sudden or unexpected change in how they behave, often becoming inattentive, confused or agitated. They may seem unmotivated or more withdrawn and unaware than usual. They may also talk about visual images that you cannot see, be more difficult to reason with, or want to walk without reason. These changes develop suddenly but may also come and go. Their behaviour is different to how they usually are. It happens when the older person becomes unwell, often with chest or bladder infections. Often this acute confusion goes away when the older person becomes well again. Older people who have dementia are particularly at risk of developing delirium and family members notice this change. It may be the reason for seeking medical or hospital care. It is hoped that understanding what this experience is like for family members will help staff to provide better support to family members in the future.

Who can participate in the research?
You are invited to participate in this research because you may have been with an older person when the older person had an acute illness and developed acute confusion/delirium. You were identified as being interested in being involved in research via the Hunter Medical Research Institute (HMRI) Research Register. This study is suitable for you if:

- You are a family member to an older person aged 65 years or more (family members are those people who feel they are part of the older person’s family – you do not have to be a blood relative, be married to or live with the older person),
- You have been with or cared for an older person when they had an acute illness and also became acutely confused (this may have been at home, in residential care or during a hospital stay),
You can communicate in English,
You are willing to meet with the researcher on at least one occasion to be interviewed, and
You are willing to be interviewed at a location within 2 hours drive Newcastle.

Your choice about participating
Participation in this research is entirely your choice. Only those family members who give their voluntary informed consent will be included in the research. Whether you decide to participate or not, your decision will not disadvantage you in any way. The only people who will know about your decision to participate or not will be the HMRI Research Register and the researchers for this study.
If you do decide to participate, you may change your mind and withdraw from the research at any time without giving a reason and without any consequence to you or your older family member. You also have the option of withdrawing your information without giving a reason.
If the researcher believes that participating in this research is upsetting to you, she will discuss this with you and may suggest you withdraw from the research.

What you will be asked to do and how much time it will take
If you agree to participate, you will be asked to meet with the researcher to be interviewed on at least one occasion. Interviews should last about one hour and will be held in a place and at a time agreeable to you. During the interview you will be asked to talk about what being with, or caring for, your acutely confused older family member was like. After your first interview you may be asked for follow-up interviews to clarify or provide more detail about your experience. Participation in these interviews is voluntary. With your consent each interview will be digitally recorded and then typed verbatim into a word document by a paid transcriber or the researcher. During the interview you can ask for the digital recorder to be stopped or for your recording to be erased.
After each interview you will be asked to read the typed version of your interview and to meet or discuss with the researcher any changes that you would like made. These discussions or meetings may vary in length but should not last more than 45 minutes. Participation in this part of the research is voluntary and will be at a time and venue that is agreeable to you.
You will also be asked to comment on a summary of the final findings of the research. Participation in this part of the research is also voluntary.
All contact with you about your involvement in the research will be made by the researcher, or the research supervisors, Professor Isabel Higgins or Professor Diana Keatinge. There will be no reimbursement or payment to participants for involvement in this research.

The risks and benefits of participating
I cannot promise you any benefit from participating in this research. It is possible that you may find the opportunity to talk about your experience to be of benefit. You may also find participation unpleasant or distressing. If you do experience any distress as a result of participation in this research please contact me and we can discuss how to access counselling or other support services.

Protection of your privacy
Any information collected by the researcher which might identify you will be stored securely and only accessed by the researcher and research supervisors named above, unless you consent otherwise or except as required by law. If you disclose specific details about an illegal incident (e.g. date, place, perpetrators) during the research, the researcher may be obliged to report the information to the Police or other authority without your consent.
Interview data will be de-identified by replacing identifying details with pseudonyms and will be stored separately to identifying data. Transcribers used to produce the typed version of your interview will be required to sign a confidentiality and data security/retention undertaking. All publications and presentations related to this research will use de-identified information and data, including the summary of results provided to participants at the end of the study. Data from this research will be retained for at least 5 years after completion of the research in a secure cabinet at the School of Nursing and Midwifery, The University of Newcastle. Data from this research will then be destroyed in accordance with The University of Newcastle Research Data and Materials Management policy and procedure. Due care will be taken to ensure that disposal is secure and takes account of the confidential nature and possible sensitivity of the data.

**How will the information collected be used?**

The data collected in this research will be reported in a thesis to be submitted for my degree, in papers in professional journals and at professional conferences or seminars. These reports may contain words said by you during an interview however you will not be identified by name. If you would like to receive a copy of a publication please contact the researcher using the contact details below.

**What you need to do to participate**

Please read this *Research Information Statement & Invitation* and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please initially contact Trisha D’Accion. Her contact details are listed in the attached letter from the HMRI Research Register. If you would like to participate, please complete the attached HMRI Study Response form and return both to the HMRI Research Register Coordinator in the reply paid envelope provided. Return of a completed consent form will be taken as your informed and voluntary consent to participate. When I receive your consent forms from HMRI I will contact you to discuss the research, answer questions you may have and to arrange a convenient interview time and location. Please keep this *Research Information Statement & Invitation* for your future reference.

**Further information and questions?**

If you would like further information or have questions about the research after you agree to participate in the study please contact:

Jenny Day Phone: 4921 2091 email: jenny.day@newcastle.edu.au
Professor Isabel Higgins Phone: 4921 6144 email: isabel.higgins@newcastle.edu.au
Professor Diana Keatinge Phone: 4921 6010 email: diana.keatinge@newcastle.edu.au

**Complaints about this research**

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Health, Reference 10/06/16/5.05 and The University of Newcastle Human Research Ethics Committee, Reference H-2010-1178. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager Research Ethics and Governance, Hunter New England Health, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, Email: Hnehrec@hnehealth.nsw.gov.au.

Thank you for considering this invitation to participate in my research.
Researcher  Research Supervisors:

Jenny Day   Dr Isabel Higgins   Dr Diana Keatinge
PhD Candidate Professor Older Person Care  Professor Paediatric Youth & Family Health Nursing
Participant Consent Form
(HMRI Research Register)

Consent Statement
I agree to participate in the research project named above and give my consent voluntarily.

I understand that the project will be conducted as described in the Research Information Statement & Invitation, a copy of which I have read and retained. I have had the opportunity to have questions answered to my satisfaction.

I understand I can withdraw from the research project at any time and do not have to give any reason for withdrawing.

I understand that my personal information will remain confidential to the researchers, except as required by law, and that publication resulting from this research will use de-identified data.

I consent to
- participating in one or more interviews and having my interviews recorded and transcribed into a typed version by a paid transcriber or the researcher.

I also consent to (please circle yes or no for each item):
Yes / No checking the content of typed versions of my interviews;
Yes / No commenting on a summary of the final results of the study.

Name (please print):__________________________________________
Signature__________________________________________ Date: ________________
Contact Details: Phone____________________ Email / Mobile phone ________________
Address_______________________________________________________________________
Age:________________________ Place of birth: ________________
Relationship to the older person who had confusion:
______________________________________________________________________________
Age of the older person:________________________

Professor Isabel Higgins, and
Professor Diana Keatinge
School of Nursing and Midwifery
Faculty of Health
The University of Newcastle
University Drive
Callaghan, NSW, 2308
Ph. 4921 6304 Fax. 4921 6301
Isabel.higgins@newcastle.edu.au
Diana.keatinge@newcastle.edu.au

Family experiences – being with, or caring for, an older person who has acute confusion
(Version 1, 20/07/2011)
APPENDIX D: INTERVIEW SCHEDULE
Interview Schedule

Research Project: Family experiences-visiting an older person who has acute confusion
(Version 2, 21/06/2010)

Researcher
Jenny Day, PhD Candidate
School of Nursing & Midwifery
The University of Newcastle

Interview settling period

- introductions
- explanation of the study including participant opportunity to review, edit or erase typed interview transcripts without explanation or justification and how participant anonymity will be protected (including data confidentiality arrangements, safeguards for the planned use of an independent transcriber, and use of pseudonyms in transcribed interviews and future publications).
- description of the interview process including the opportunity for future interviews, estimated interview duration and participant freedom to refuse to answer any question or end the interview at any time without reason or to decline further interviews.
- advise that information which might identify the participant will not be disclosed without participant consent except if they disclose specific details about an illegal incident (e.g. date, place, and perpetrators) or questionable practice. Should such a disclosure occur the researcher may be obliged to report the information to the Police or other recognized authority without their consent.
- request permission to take brief field notes during the interview, for the participant to not fully identify themselves or other people during the digital recording period and ask for permission to use the participant’s first name. The participant’s voluntary consent to be interviewed and having the interview recorded digitally will be confirmed.
- explanation of acute confusion/delirium in lay terms
- provide an opportunity for and invite participant questions
- advise when the interview/digital recording commences.

Opening and possible follow-up open questions

Opening
I am interested in understanding what it was like for you to visit your older family member in hospital when they had acute confusion/delirium.

- Can tell me about how you found out that your older family member was in hospital and confused?
- Can tell me about one of your visits to the hospital from the beginning?

Possible follow-up questions dependent on participant response

- Can you describe for me how they were when you visited?
- What was this like for you?
- When you were with them what went through your mind?
- How were you feeling?
- Can you describe for me what you expected and how this was different?
- What did you find had changed about your relationship with them?
- Can you tell about what helped you with what was happening?
- Have there been other times when you have experienced this same problem?
- Can they think of or suggest any material that illustrates what you think experiencing delirium is like (e.g. photo, song, poem or painting)

**Example encouraging statements**
- Can you please tell me more about ....
- What did you make of that?
- What were you most worried about?
- Go on, Uh huh, or Mm hum

**Concluding questions**
- is there anything else you would like to share with me?
- is there anything else you think I should know about your experience?
- if you had the opportunity to give advice to other family’s about to have the same experience as you, what would that advice be?

**Closing the interview**
- thanks for sharing their story and giving me their time – appreciate their interest and their information is valuable to me
- advise that I will be in contact to provide a copy of the transcript of their interview and confirm if they would like to read and check it’s content,
- confirm the opportunity to edit, erase or confirm interview content and invite to do this
- raise the possibility of future interviews (if interested and feel you would like to tell me more)
- ask for an indication of interest in commenting on a summary of the final results of the study and/or receiving feedback on the results of the study when the research is completed
- indicate when the digital recorder is turned off
- spend a period of time with the participant to debrief their experience and further acknowledge the participant’s contribution
Interview Schedule

Research Project: Family experiences – being with or caring for an older person who has acute confusion

(Version 1, 20/07/2011)

Researcher
Jenny Day, PhD Candidate
School of Nursing & Midwifery
The University of Newcastle

Interview settling period
- introductions
- explanation of the study including participant opportunity to review, edit or erase typed interview transcripts without explanation or justification and how participant anonymity will be protected (including data confidentiality arrangements, safeguards for the planned use of an independent transcriber, and use of pseudonyms in transcribed interviews and future publications).
- description of the interview process including the opportunity for future interviews, estimated interview duration and participant freedom to refuse to answer any question or end the interview at any time without reason or to decline further interviews.
- advise that information which might identify the participant will not be disclosed without participant consent except if they disclose specific details about an illegal incident (e.g. date, place, and perpetrators) or questionable practice. Should such a disclosure occur the researcher may be obliged to report the information to the Police or other recognized authority without their consent.
- request permission to take brief field notes during the interview, for the participant to not fully identify themselves or other people during the digital recording period and ask for permission to use the participant’s first name. The participant’s voluntary consent to be interviewed and having the interview recorded digitally will be confirmed.
- explanation of acute confusion/delirium in lay terms
- provide an opportunity for and invite participant questions
- advise when the interview/digital recording commences.

Opening and possible follow-up open questions
Opening
I am interested in understanding what it was like for you to be with your older family when they were unwell and had acute confusion/delirium.
- Can tell me about how you found out that your older family member was confused?
- Can tell me about one of the times they were acutely confused, from the beginning?
Possible follow-up questions dependent on participant response

- Can you describe for me how they were when you were with them?
- What was this like for you?
- When you were with them what went through your mind?
- How were you feeling?
- Can you describe for me what you expected and how this was different?
- What did you find had changed about your relationship with them?
- Can you tell about what helped you with what was happening?
- Have there been other times when you have experienced this same problem?
- Can they think of or suggest any material that illustrates what you think experiencing delirium is like (e.g. photo, song, poem or painting)

Example encouraging statements

- Can you please tell me more about ....
- What did you make of that?
- What were you most worried about?
- Go on, Uh huh, or Mm hum

Concluding questions

- is there anything else you would like to share with me?
- is there anything else you think I should know about your experience?
- if you had the opportunity to give advice to other family’s about to have the same experience as you, what would that advice be?

Closing the interview

- thanks for sharing your story and giving me your time – appreciate their interest and indicate their information is valuable to me
- advise that I will be in contact to provide a copy of the transcript of their interview and confirm if they would like to read and check it’s content,
- confirm the opportunity to edit, erase or confirm interview content and invite to do this
- raise the possibility of future interviews (if interested and feel you would like to tell me more)
- ask for an indication of interest in commenting on a summary of the final results of the study and/or receiving feedback on the results of the study when the research is completed
- indicate when the digital recorder is turned off
- spend a period of time with the participant to debrief their experience and further acknowledge the participant’s contribution
APPENDIX E: TRANSCRIBER UNDERTAKING
Research Project: Family experiences-visiting an older person who has acute confusion
(Version 1, 22/05/2010)

Researcher
Jenny Day, PhD Candidate
School of Nursing & Midwifery
University of Newcastle

I, ……………………………………………., am aware of the importance of keeping confidential information that may be revealed to me during transcription of individual interviews from Jenny Day’s research project. I am aware that during these transcriptions I may be privy to information about individuals that is of a private and personal nature. I realise that by signing this document, I undertake not to reveal any of the information contained in any of these interviews to any other person. I also realise that by signing this document, I undertake to store electronic and digital files of each interview on a password protected computer which is only accessed by me, and to delete these files when Jenny Day indicates that the transcription is complete and correct. I also undertake not to distribute digital interview records nor transcribed interview files to anyone other than Jenny Day.

Name: …………………………………………………
Signed: …………………………………………………

Organisation……………………………………
Address………………………………………………

Date:………………………………

Witness Name: ………………………………………
Witness Signature: …………………………………

Date: …………………………

Transcriber Confidentiality & Data Security/ Storage Undertaking
APPENDIX F: HUMAN RESEARCH ETHICS APPROVALS
23 June 2010

Professor I Higgins
School of Nursing and Midwifery
University of Newcastle

Dear Professor Higgins,

Re: The lived experience of family members who visit a hospitalized older person when the older person has delirium (10/06/16/5.05)

HNEHREC Reference No: 10/06/16/5.05
NSW HREC Reference No: HREC/10/HNE/140
NSW SSA Reference No: SSA/10/HNE/165

Thank you for submitting the above protocol for single ethical review. This project was first considered by the Hunter New England Human Research Ethics Committee at its meeting held on 16 June 2010. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review. The Committee’s Terms of Reference are available from the Hunter New England Area Health Service website: http://www.hnehealth.nsw.gov.au/Human_Research_Ethics.

I am pleased to advise that following acceptance under delegated authority of the requested clarifications and revised documentation by Dr Nicole Gerrand, Manager, Research Ethics & Governance, the Hunter New England Human Research Ethics Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

- For the Participant Study Information Pack – Adult Family Members, contents include:
  - Participant Study Information Pack Envelope (Version 2 dated 21 June 2010);
  - Research Information Statement and Invitation – Adult (Version 2 dated 21 June 2010);
  - Participant Consent Form – Adult (Version 1 dated 22 May 2010);
  - Addressed Reply Paid Envelope;
- For Participant Study Information Pack - Family Member 13 to 18 years of age, contents include:
  - Participant Study Information Pack Envelope (Version 2 dated 21 June 2010);
  - Research Information Statement and Invitation – 13 to <18 years (Version 2 dated 21 June 2010);
  - Participant Consent Form – 13 to <18 years (Version 1 dated 22 May 2010);
  - The Addressed Reply Paid Envelope;

Hunter New England Research Ethics & Governance Unit

Locked Bag No 1
New Lambton NSW 2305
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email: hnehrec@hnehealth.nsw.gov.au
- For the Participant Study Information Pack – Large Print (adult), contents include:
  ▪ Participant Study Information Pack Envelope (Version 2 dated 21 June 2010);
  ▪ Research Information Statement and Invitation – Large print (adult) (Version 1 dated 21 June 2010);
  ▪ Participant Consent Form – Large print (adult) (Version 1 dated 22 May 2010);
  ▪ Addressed Reply Paid Envelope;
- For the Ward Poster (Version 2 dated 21 June 2010);
- For the Interview Schedule (Version 2 dated 21 June 2010);
- For the Follow-Up Interview Schedule (Version 1 dated 21 June 2010);
- For the Recruiter Information Pack, contents include:
  ▪ Recruitment Information for NUMs/CNC (Version 2 dated 21 June 2010);
  ▪ Participant Inclusion Criteria;
  ▪ CAMI Assessment Tool;
  ▪ Copy of the Participant Study Information Pack; and
- For the Transcriber Confidentiality & Data Security/Storage Undertaking

For the protocol: The lived experience of family members who visit a hospitalized older person when the older person has delirium

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of this letter, after which a renewal application will be required if the protocol has not been completed.

The National Statement on Ethical Conduct in Human Research (2007), which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

- A report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is June 2011. A proforma for the annual report will be sent two weeks prior to the due date.

- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.

- All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.

- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
  - any serious or unexpected adverse events
    - Adverse events, however minor, must be recorded as observed by the Investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the Investigator or his deputies considers the event to be related to the trial substance or procedure. These do not need to be reported to the Hunter New England Human Research Ethics Committee

Hunter New England Research Ethics & Governance Unit

(Locked Bag No 1)  
(New Lambton NSW 2305)  
Telephone (02) 49214 950 Facsimile (02) 49214 818  
Email: hnehrec@hnehealth.nsw.gov.au  

355
- Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Manager, Research Ethics & Governance, of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.


- Serious adverse events are defined as:
  - Causing death, life threatening or serious disability.
  - Cause of prolong hospitalisation.
  - Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.

- Unforeseen events that might affect continued ethical acceptability of the project.

- If for some reason the above protocol does not commence (for example it does not receive funding), is suspended or discontinued, please inform Dr Nicole Gerrand, as soon as possible.

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Should you have any concerns or questions about your research, please contact Dr Gerrand as per her details at the bottom of the page. The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Please quote 10/06/19/5.05 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Dr M Parsons
Chair
Hunter New England Human Research Ethics Committee
28 June 2010

Professor I Higgins
School of Nursing and Midwifery
University of Newcastle

Dear Professor Higgins,

Re: The lived experience of family members who visit a hospitalized older person when the older person has delirium (10/08/16/5.05)

HNEHREC reference number: 10/06/16/5.05
HREC reference number: HREC/10/HNE/140
SSA reference number: SSA/10/HNE/185

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

- John Hunter Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Dr Nicole Gerrand
Research Governance Officer
Hunter New England Health

Hunter New England Research Ethics & Governance Unit
(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49214 190 Fax/TTY (02) 49214 516
Email: hnehrec@hnehealth.nsw.gov.au
29 October 2010

Professor I Higgins
School of Nursing and Midwifery
University of Newcastle

Dear Professor Higgins,

Re: The lived experience of family members who visit a hospitalized older person when the older person has delirium (10/06/16/5.05)

HNEHREC Reference No: 10/06/16/5.05
NSW HREC Reference No: HREC/10/HNE/140
NSW SSA Reference No: SSA/10/HNE/165

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has granted ethical approval for the following amendment requests:

- To extend the existing recruitment process and recruitment personnel to include older people who are being treated by the medical/surgical teams of the current wards within the John Hunter Hospital, known as outlying patients;
- For the Study Inclusion Criteria (Version 2 dated 20 October 2010), and
- For the Recruitment Information for NUMs/CNC (Version 3 dated 20 October 2010)

For the protocol: The lived experience of family members who visit a hospitalized older person when the older person has delirium

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of the approval letter of your initial application, after which a renewal application will be required if the protocol has not been completed. The above protocol is approved until June 2013.

The National Statement on Ethical Conduct in Human Research (2007) which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfil this function, it requires:

- a report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is June 2011. A proforma for the annual report will be sent two weeks prior to the due date.

Hunter New England Human Research Ethics Committee
(Locked Bag No 1)
(New Lambton NSW 2305)
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email hnehrec@hnehealth.nsw.gov.au
Nicola.germon@hnehealth.nsw.gov.au
Michelle.ianc@hnehealth.nsw.gov.au
• A final report be submitted at the completion of the above protocol, that is after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.

• All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.

• The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
  - any serious or unexpected adverse events
    • Adverse events, however minor, must be recorded as observed by the investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the investigator or his deputies considers the event to be related to the trial substance or procedure.
    • Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.
    • Copies of serious adverse event reports from other sites should be sent to the Hunter New England Human Research Ethics Committee for review as soon as possible after being received.
  - Serious adverse events are defined as:
    • Causing death, life threatening or serious disability.
    • Cause or prolong hospitalisation.
    • Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.
    • Unforeseen events that might affect continued ethical acceptability of the project.

• If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand, the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Area Health Service. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per her contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Area Health Service website:

Internet address: http://www.hnehealth.nsw.gov.au/Human_Research_Ethics

Please quote 10/06/16/5.05 in all correspondence.

Hunter New England Human Research Ethics Committee

Locked Bag No 1
New Lambton NSW 2305
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email hnehrce@hnehealth.nsw.gov.au
Nicole.gerrand@hnehealth.nsw.gov.au
Michelle.lane@hnehealth.nsw.gov.au
The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For:  Dr M Parsons
Chair
Hunter New England Human Research Ethics Committee
2 May 2011

Hunter New England
NSW Health

Professor I Higgins
School of Nursing & Midwifery
University of Newcastle

Dear Professor Higgins

Re: The lived experience of family members who visit a hospitalized older person when the older person has delirium (10/06/16/5.05)

HNEHREC Reference No: 10/06/16/5.05
NSW HREC Reference No: HREC/10/HNE/140
SSA Reference No: SSA/10/HNE/165

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council’s National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has granted ethical approval for the following amendment requests:

- For the addition of Ms Alison Clinton as research assistant;
- For the addition of Ms Kelly Musgrave as research assistant;
- For the removal of Ms Wendy Goodman as research assistant; and
- For the amendment to the older person inclusion criteria to enhance family member recruitment opportunities

For the protocol The lived experience of family members who visit a hospitalized older person when the older person has delirium

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of the approval letter of your initial application, after which a renewal application will be required if the protocol has not been completed. The above protocol is approved until June 2013.

The National Statement on Ethical Conduct in Human Research (2007) which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfill this function, it requires:

Hunter New England Human Research Ethics Committee
(Locked Bag No 1)
New Lambton NSW 2305
Telephone (02) 49214 950 Facsimile (02) 49214 618
Email: hnehrec@hnehealth.nsw.gov.au
• A report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is June 2011. A proforma for the annual report will be sent two weeks prior to the due date.

• A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.

• All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.

• The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
  - any serious or unexpected adverse events
    - Adverse events, however minor, must be recorded as observed by the Investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the Investigator or his deputies considers the event to be related to the trial substance or procedure.
    - Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.
    - Copies of serious adverse event reports from other sites should be sent to the Hunter New England Human Research Ethics Committee for review as soon as possible after being received.
  - Serious adverse events are defined as:
    - Causing death, life threatening or serious disability.
    - Cause or prolong hospitalisation.
    - Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.
    - Unforeseen events that might affect continued ethical acceptability of the project.

• If for some reason the above protocol does not commence (for example it does not receive funding), is suspended or discontinued, please inform Dr Nicole Gerrand, the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Area Health Service. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Area Health Service website; Internet address: http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

Hunter New England Human Research Ethics Committee
(Locked Bag No 1)
New Lambton NSW 2305
Telephone (02) 49214 500 Facsimile (02) 49214 816
Email hnehREC@hnehealth.nsw.gov.au
Please quote 1006/18/5.05 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For:  Associate Professor M Pancora
       Chair
       Hunter New England Human Research Ethics Committee
5 August 2011

Professor I Higgins
School of Nursing & Midwifery
University of Newcastle

Dear Professor Higgins

Re: The lived experience of family members who are with an older person when the older person has delirium (10/06/16/5.05)

HNEHREC Reference No: 10/06/16/5.05
NSW HREC Reference No: HREC/10/HNE/140
SSA Reference No: SSA/10/HNE/165

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed by the Hunter New England Human Research Ethics Committee. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research (2007) (National Statement) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has granted ethical approval for the following amendment requests:

- For the change of study title to “The lived experience of family members who are with an older person when the older person has delirium”;
- For the revision of the research aim and question;
- For the addition of research strategies;
- To amend older person inclusion criteria;
- To amend family member inclusion criteria;
- For the addition of an interview schedule;
- To amend the research timetable;
- For the Community Member Research Information Statement and Invitation (Version 1 dated 20 July 2011);
- For the HMRI Research Register Member Research Information Statement and Invitation (Version 1 dated 20 July 2011);
- For the Support Group Member Research Information Statement and Invitation (Version 1 dated 20 July 2011);
- For the HMRI Research Register, Support Group or Community Member Participant Consent Form (Version 1 dated 20 July 2011);
- For the HMRI Research Register, Support Group or Community Member Interview Schedule (Version 1 dated 20 July 2011);
- For the Newspaper Advertisement (Version 1 dated 20 July 2011); and
- For the Newspaper Media Release (Version 1 dated 20 July 2011)

Hunter New England Human Research Ethics Committee
Locked Bag No 1
New Lambton NSW 2305
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email:hnehrec@hnehealth.nsw.gov.au
For the protocol: The lived experience of family members who visit a hospitalized older person when the older person has delirium

Approval from the Hunter New England Human Research Ethics Committee for the above protocol is given for a maximum of 3 years from the date of the approval letter of your initial application, after which a renewal application will be required if the protocol has not been completed. The above protocol is approved until June 2013.

The National Statement on Ethical Conduct in Human Research (2007) which the Committee is obliged to adhere to, include the requirement that the committee monitors the research protocols it has approved. In order for the Committee to fulfill this function, it requires:

- A report of the progress of the above protocol be submitted at 12 monthly intervals. Your review date is June 2012. A proforma for the annual report will be sent two weeks prior to the due date.

- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled. A proforma for the final report will be sent two weeks prior to the due date.

- All variations or amendments to this protocol, including amendments to the Information Sheet and Consent Form, must be forwarded to and approved by the Hunter New England Human Research Ethics Committee prior to their implementation.

- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
  - Any serious or unexpected adverse events
    - Adverse events, however minor, must be recorded as observed by the investigator or as volunteered by a participant in this protocol. Full details will be documented, whether or not the investigator or his deputies considers the event to be related to the trial substance or procedure.
    - Serious adverse events that occur during the study or within six months of completion of the trial at your site should be reported to the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible and at the latest within 72 hours.
    - Copies of serious adverse event reports from other sites should be sent to the Hunter New England Human Research Ethics Committee for review as soon as possible after being received.
    - Serious adverse events are defined as:
      - Causing death, life threatening or serious disability.
      - Cause or prolong hospitalisation.
      - Overdoses, cancers, congenital abnormalities whether judged to be caused by the investigational agent or new procedure or not.
      - Unforeseen events that might affect continued ethical acceptability of the project.

Hunter New England Human Research Ethics Committee
Locked Bag No 1
New Lambton NSW 2305
Telephone (02) 49214 950 Facsimile (02) 49214 818
Email: hnehrec@hnehealth.nsw.gov.au
• If for some reason the above protocol does not commence (for example if it does not receive funding), is suspended or discontinued, please inform Dr Nicole Gerrand, the Professional Officer of the Hunter New England Human Research Ethics Committee as soon as possible.

The Hunter New England Human Research Ethics Committee also has delegated authority to approve the commencement of this research on behalf of the Hunter New England Local Health District. This research may therefore commence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the Hunter New England Local Health District website:

Internet address: http://www.hnehealth.nsw.gov.au/research_ethics_and_governance_unit

Please quote 19/06/10/3/5.05 in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Associate Professor M Parsons
Chair
Hunter New England Human Research Ethics Committee
HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

| To Chief Investigator or Project Supervisor: | Professor Isabel Higgins |
| Cc Co-investigators / Research Students: | Ms Alison Clinton  
| | Ms Kelly Musgrave  
| | Professor Diana Keatinge  
| | Mrs Jennifer Day |
| Re Protocol: | The lived experience of family members who are with an older person when the older person has delirium |
| Date: | 22-Sep-2011 |
| Reference No: | H-2010-1178 |

Thank you for your Variation submission to the Human Research Ethics Committee (HREC) seeking approval in relation to a variation to the above protocol.

Variation to:

1. Change the study title to 'The lived experience of family members who are with an older person when the older person has delirium'

2. Revise the research aims and question

3. Amend the inclusion criteria for older people and family member participants.

4. Add an interview schedule and research timetable

- Community Members Research Participant Information Statement and Invitation, Version 1 dated 20.7.2011
- HMRI Research Register Member Information Statement
- Support Group Member Participant Information Statement and Invitation, Version 1 dated 20.7.2011
- HMRI Research Register, Support Group or Community Member Participant Consent Form, Version 1 dated 20.7.2011
- HMRI Research Register, Support Group or Community Member Interview Schedule, Version 1 dated 20.7.2011
- Newspaper Advertisement, Version 1 dated 20.7.2011
- Newspaper Media Release, Version 1 dated 20.7.2011

Your submission was considered under Expedited Review of External Approval review by the Chair/Deputy Chair.
I am pleased to advise that the decision on your submission is **External HREC Approval Noted** effective 14-Sep-2011.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request.

Professor Alison Ferguson  
Chair, Human Research Ethics Committee

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*For communications and enquiries:*  
**Human Research Ethics Administration**

Research Services  
Research Integrity Unit  
HA149, Hunter Building  
The University of Newcastle  
Callaghan NSW 2308  
T +61 2 492 18999  
F +61 2 492 17184  
Human-Ethics@newcastle.edu.au

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*Linked University of Newcastle administered funding:*

<table>
<thead>
<tr>
<th>Funding body</th>
<th>Funding project title</th>
<th>First named investigator</th>
<th>Grant Ref</th>
</tr>
</thead>
</table>
APPENDIX G: DATA ANALYSIS ILLUSTRATIONS
<table>
<thead>
<tr>
<th>Data Analysis</th>
<th>Beth [p7]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reawakening each woman’s experiences in my mind</td>
<td>Reading and re-reading each transcript and re-listening to the digital recording of interview over time. Notation of speech emphases, emotional reactions and hand gestures in the transcript.</td>
</tr>
<tr>
<td>Highlighting important words, phrases and statements in transcripts – those that are revealing for each woman’s experience</td>
<td>He didn’t know where he was. He didn’t know who we were. I think that was the night time when he was here. He didn’t know what was happening. He opened the wardrobe door and was going to pee in the wardrobe because he thought he was in the bathroom. And I guess that’s my terminology (chuckle) to say he’s not with us, his mind is not with us. Physically he is (Beth [p7] – l2 – p28).</td>
</tr>
<tr>
<td>Exploring highlighted text and asking/questioning what was meant for each woman</td>
<td>What’s not with Beth? He’s not. What or who is ‘He’? How do you know? What is it like? But ‘He’ is – his body.</td>
</tr>
<tr>
<td>Consulting field notes and interview reflections</td>
<td>Is this new? Does only Beth experience her husband as gone? Is this new change suggesting presence is not always certain/is fragile?</td>
</tr>
<tr>
<td>Making notes about meaning and questions to consider</td>
<td>Her husband, as she knows him, is gone though he is there? How can this be – living a contradiction? Not what she is expecting. Different to how things are usually in her life – he is with her as a person and as one. Corporeally he is there – so what is gone? What is missing, how does Beth know, and what does this mean for her?</td>
</tr>
<tr>
<td>Isolation and recording of emergent tentative themes – using each woman’s words</td>
<td>Losing Him: … he’s not with us (Beth [p7] – l2 – p28).</td>
</tr>
<tr>
<td>Discussion with supervisors about interpretations, emerging themes, with subsequent reflection and revision of themes.</td>
<td>Aloneness or isolation Losing Him / Losing a Loved One Out of my reach Away</td>
</tr>
<tr>
<td>Bringing together of themes for all women</td>
<td>The person the women know is not present as they expect. They are no longer familiar to them as a person though they are corporeally present – no longer like their mental image of them. The person is gone unexpectedly – no longer in-person as they should be.</td>
</tr>
<tr>
<td>Turning to novels, poetry, children’s books, music, etymological origins of terms.</td>
<td>The operation was quite routine. But my father somewhat troubled, Subtly not there; with us but not of us. (Young, 2012)</td>
</tr>
<tr>
<td>Turning to phenomenological writings</td>
<td>Social world – lived body and body of others The look/gaze at another person. Embodiment – in-person Taken-for-grantedness To expect someone but to find they are not present. expect, lack and absence (Sartre, 2003)</td>
</tr>
<tr>
<td>Reworking of text and changing the thematic wordings to capture meanings conveyed in the women’s descriptions:-</td>
<td><strong>Sub-theme</strong> Facing a loved one’s existential absence <strong>Theme</strong> Living the fragility of a loved one’s presence <strong>Essence</strong> Changing family portraits: Sudden existential absence during delirium</td>
</tr>
</tbody>
</table>
Illustration 2: Gemma [p12]

<table>
<thead>
<tr>
<th>Data Analysis</th>
<th>Gemma [p12]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reawakening each woman’s experiences in my mind</td>
<td>Reading and re-reading each transcript and re-listening to the digital recording of interview over time. Notation of speech emphases, emotional reactions and hand gestures in the transcript.</td>
</tr>
<tr>
<td>Highlighting important words, phrases and statements in transcripts – those that are revealing for each woman’s experience</td>
<td>And by the time you got to that stage dad was, I don’t think he comprehended it... you know, what you wanted to say, he was past that. And I was thinking it was more like at times dad was a complete stranger. It was not dad anymore, it was a complete stranger. That’s how I felt. (Gemma [p12] – I2 – p2)</td>
</tr>
<tr>
<td>Exploring highlighted text and asking/questioning what was meant for each woman</td>
<td>Why is her dad a stranger? What is it that has changed? Why is he a stranger to her now? What is this like for her? Where is the man she knows if he is gone/now a stranger?</td>
</tr>
<tr>
<td>Consulting field notes and interview reflections</td>
<td>Is this madness and shame? Does she distance herself? Have other people noticed that her dad is a stranger to her?</td>
</tr>
<tr>
<td>Making notes about meaning and questions to consider</td>
<td>Her dad, as she knows him, is gone though he is there? How can this be – living a contradiction or disembodiment? Not what she is expecting. Different– corporeally he is there – so who is she with? Who is present? What does this mean for her?</td>
</tr>
<tr>
<td>Isolation and recording of emergent tentative themes – using each woman’s words</td>
<td>Being with someone new/ knowing dad anew - a stranger: … dad was a complete stranger. It was not dad anymore, it was a complete stranger. (Gemma [p12] – I2 – p2)</td>
</tr>
<tr>
<td>Discussion with supervisors about interpretations, emerging themes, with subsequent reflection and revision of themes.</td>
<td>It wasn’t normal or usual – expect presence whilst living Knowing dad anew Lost to somewhere – to another world Aloneness</td>
</tr>
<tr>
<td>Bringing together of themes for all women</td>
<td>The person with the women is different to the person they expected – so different they are foreign. They are changed and no longer familiar to them as a person. Even though they are corporeally present a new and different person is within their loved one’s corporeal presence. The person is a stranger to them - an in-stranger.</td>
</tr>
<tr>
<td>Turning to novels, poetry, children’s books, music, etymological origins of terms.</td>
<td>Of blazing, crazy hues. Of ghostly faces, horrid forms. Evil voices murmuring evil thoughts. (Young, 2012)</td>
</tr>
<tr>
<td>Turning to phenomenological writings</td>
<td>Social world – lived body and body of others The look/gaze at another person and their look back at me. Embodiment – in-stranger Taken-for-grantedness To expect someone to find they are not present but another presence / spirit (Merleau-Ponty,2002/04 ) is with them.</td>
</tr>
<tr>
<td>Reworking of text and changing the thematic wordings to capture meanings conveyed in the women’s descriptions:- Arrival at sub-theme Arrival at themes Arrival at the essence</td>
<td>Sub-theme Living with a stranger Theme Living the fragility of a loved one’s presence Essence Changing family portraits: Sudden existential absence during delirium</td>
</tr>
</tbody>
</table>