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Holding on while letting go:

Trauma and growth on the pathway of dementia care in families

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Abstract

Objectives: Limited research explores the medical model of residential care in dementia from the family caregiver's perspectives.

Method: This study sought subjective interpretations of nine family caregivers who experienced relinquishing their status as primary caregiver to a medical model, dementia care residential setting. Following semi-structured interviews and transcription data was analysed using interpretative phenomenological analysis (IPA).

Results: One superordinate theme, *Navigating 'system' control*, overarched three subordinate themes: *Connecting/Disconnecting*, *Windows Closing*, and *Capacity for Sensation*. *Navigating System control* reflected participants' experience of circumnavigating a medical system fraught with hierarchical challenges inclusive of a complex maze of contradictions; that appeared threatening yet at times comforting; authoritarian yet often humane. For them, care of self, while advocating for a family member with dementia, required vigilance to manoeuvre a system of care that imposed its uninvited authority at will. *Connection/disconnection* highlights the enduring struggle for inclusivity in caregiving despite the omnipresent trauma of *windows closing*. Psychological growth came to these participants through a unexpected *capacity for sensation* which offered a unique lens to communication with the family member with dementia primarily through sensory exchange.

Conclusions: Models of dementia care and therapeutic interventions could inclusively involve dementia family caregivers who may be experiencing traumatic distress, and associated guilt, stigma, loss and grief. Co-existing psychological wellbeing however, is possible when family members are encouraged to transition communication to sensory awareness and exchange as *windows close*.

Keywords: *interpretative phenomenological analysis (IPA), medical model of dementia care, families and dementia, trauma, growth and psychological wellbeing.*

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Trauma and growth on the pathway of dementia care in families.

Introduction

There is a paucity of research exploring dementia family caregivers' experience of transitioning a family member from home care to institutionalised care framed within a medical model. This journey can be fraught with uncharted territory and is potentially traumatic. For many, it can be a formidable trek through systems that are focused on medical wellbeing seemingly lacking inclusivity of the individual experiences, and psychosocial challenges for families (Walmsley & McCormack, 2014a; 2014b). By exploring family caregiver experiences of transition to hospitalisation and its sequelae, new insights into the psychological impact of the dementia journey on all family members can better inform health policy and care protocols (Runge, Gilham & Peut, 2009; Walmsley & McCormack, 2014a). This interpretative phenomenological study explores both positive and negative 'lived' experiences of the dementia journey from the subjective perspective of family caregivers. Specifically, it seeks to understand the psychosocial experiences of relinquishing care of a loved one with severe stage dementia entering residential care that is underpinned by a medical model of care.

Dementia is a leading disease burden and cause of death in developed countries (ABS, 2013, Alzheimer's Association, 2015; ONS, 2014; WHO, 2015). Worldwide, over half of those living in residential aged care services have dementia, and numbers are expected to rise with population ageing (AIHW, 2012; AIHW, 2013; Alzheimer's Association, 2015; WHO 2012, 2015). As a consequence, care of those with dementia will become significantly reliant on health and aged care services, further complicated by co-morbid conditions, and ongoing

cumulative loss of identity (Clare, 2003). That care is further complicated in later stage dementia when familiar people are no longer recognised, judgements and problem solving skills dissipate, speech becomes limited, and individuals experience increasing reliance on personal care by others (AIHW, 2012).

The term *family caregiver* refers to family members who provide continual care for a loved one with dementia. External dementia care providers will attest to the description of the caregiver as the second patient (WHO, 2012), as they struggle to meet the demands of caring for their loved one. Psychotic like symptoms, delusions, agitation/aggression and irritability are known to cause the most anguish (Fauth & Gibbons, 2014). As such, care takers are at risk of vicarious transmission of distress as they care for others, particularly if they are susceptible to emotional contagion (Figley, 1998). Many suffer the effects of burnout, overwhelmed by the enormity of the task of caring (McCormack & Joseph, 2012; McCormack & Adams, 2015).

Understanding the distress that many caretakers experience is underpinned by constructivist self-development theory (McCann & Pearlman, 1992) and systemic trauma theory (Figley, 1998). Constructivist self-development theory (CSDT) combines object relations, self-psychology, and social cognition theories. It explains how individuals adapt to traumatic events according to the individual's unique and prior life experiences that have shaped strategies for coping, tolerance for self-regulation, and belief systems. Similarly, systemic trauma theory (Figley, 1998) explains the contagion effect of close and long term contact with emotionally-disturbed persons. Through empathy and emotional support for a significant other traumatised person, a caregiver may begin to oscillate between seeking to rescue on one hand, yet contradictorily distancing themselves emotionally on the other in response to feelings of helplessness (Figley, 1998).

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Much of that helplessness is related to family caregivers' experience of relinquishing care which is described as negative (Carradice, Shankland, & Beail, 2002). Dementia and its diagnostic label brings stigma and embarrassment to families especially if they sense potential judgment and loss of agency for their loved one. In response family members may distance themselves from support (Walmsley & McCormack, 2015a) that could assist in addressing depression, strain, social isolation, financial difficulties, and irregular sleep patterns (Parker, Mills & Abbey, 2008).

Balancing dementia care recipient needs against caregivers' personal needs is constant and dilemmas surface when individuals experience conflict between wanting to retain original relationship and managing inevitable change (Quinn, Clare, & Woods, 2013). The effects on relationship quality, when roles change and one person becomes the caregiver and the other care recipient in dementia, cannot be discounted (Quinn, Clare, & Woods, 2009). Initial contact with General Practitioners (GP) can be fraught with difficulties when lack of conceptualised dementia frameworks collide with emotional responses GP's may have in determining diagnosis (Edwards, Voss, & Iliffe, 2014; Phillips, Pond & Goode, 2011). Peel and Harding, (2014) describe services available for family and dementia care recipients as systemic mazes to be navigated. Furthermore, generally biomedical models focus primarily on biological understanding and treatment. Consequently, symptomology as the organising principle for investigation is unwarranted (Joseph et al, 2009), particularly in dementia care models, as dementia encompasses all aspects of the biopsychosocial needs of these individuals and their family networks.

Complicating the dementia care narrative is the likelihood that dementia care recipients will experience numerous care transitions prior to permanent residential placement. Almost three quarters of dementia care recipients' transition from a hospital setting to a nursing facility (Callahan et al, 2012). For all concerned the domino effects that ensues,

impacted by political funding within health systems, adds to stressful uncertainty and challenges (Callahan, et al, 2001).

However, despite anguish at observing a loved one traverse these uncertain pathways, and in keeping with literature on caregiving in psychosis (Kuipers, Onuware & Bebbington, 2010), relationship quality prior to dementia onset, can influence positive experiences (Nelis, Clare, & Whitaker, 2014; Hanson & Clarke, 2013). Some dementia caregivers report positive experiences and personal growth as gaining more patience, self-respect and personal awareness (Lloyd, Patterson, & Muers, 2015). Even when relational barriers have been reported, psychological growth has been found to co-exist with distress in dementia (Walmsley & McCormack, 2014a, 2014b, 2015a).

In defining psychological adjustment to adversity, Joseph (2011) argues that people have an innate propensity for growth. Complementary theories of psychological growth account for its possibility amidst adversity, each theory targeting various levels of growth (Joseph & Linley, 2006). The functional-descriptive model conceptualises a ruminative non-conscious process for rebuilding of shattered pre-trauma schemas into new cognitive schemas that incorporate traumatic experiences (Tedeschi & Calhoun, 2004). Aligning with this, organismic valuing theory (OVP) (Joseph & Linley, 2005), integrates person-centred perspectives recognising that individuals are naturally motivated toward cognitive incorporation of traumatic experiences within a context of positive support (Joseph, 2004).

However, later stage dementia presents unique ongoing and challenging situations of distress for families, not least the ever increasing loss of opportunity to communicate or resolve any outstanding interpersonal disputes. Uncommon mediums for communication have been found useful for some families (Walmsley & McCormack, 2014a). For example, a sense of touch appears to remain constant despite decline in senses of sight, hearing, smell and taste (Nicholls, Chang, Johnson, & Edenborough, 2013). Indeed, therapists able to

kinaesthetically empathise with dementia care recipients, can gain insight into how the individual feels or is experiencing (Coaten & Newman-Bluestein, 2013). The Australian dementia care program *Namaste Care* recognises those with dementia are capable of both initiating and being recipients of touch, facilitating communication and thereby opportunities for connecting positively with family caregivers. However, further research is required exploring the meaning family caregivers develop through this medium of communication.

Despite the wealth of research investigating dementia, little explores the medical model approach to dementia care from family caregivers' perspectives. This gap is perceived to occur as dementia care currently adopts symptomology as the organising principle of investigation and care. From this premise, shedding light on the experiences of families traversing the challenge of dementia care in later stage dementia maybe be better explored through an idiographic, interpretative approach. Therefore, this study explores subjective interpretations of this poorly researched phenomenon. It is concerned with both positive and negative experiences from relinquishing care through to institutionalised care within a medical framework for care in the later stages of dementia, and the subsequent impact on reciprocal relational intimacy of dementia families.

Methodology

Participants

Following university human ethics clearance, the directors of residential aged care facilities (RACFs) were approached to recruit families supporting a loved one in severe stage dementia residing in residential care. To meet criterion for inclusion, one family member needed to be an in-resident family member in the later stage of dementia as assessed by these directors using the Clinical Dementia Rating Scale (CDR: Morris, 1993). Three aged care facilities (RACFs) provided family groups with information about the study. Those who chose to participate contacted the researcher directly and were given consent forms prior to

interview. All family members with guardianship provided written consent for the resident family member. In all, nine participants from five families provided demographic information including caregivers' age, relationship, age of their loved one living with dementia, and length of time caring for their loved one (see Table 1). Pseudonyms were used throughout. All primary caregivers were female and those living with dementia included four male and one female. Age of primary caregivers ranged from 53 to 80 and dementia patient age ranged from 70 to 84 and average length of time caring was 5.3 years.

Insert Table 1

Data Collection

As an interpretative phenomenological study, a semi-structured interview was designed using a tunnelling technique to elicit rich data regarding the specific phenomenon under investigation (see Appendix 1: Smith, 1996). Participants were interviewed in a place of their own choosing, either within the aged care facility or their home. Interviews were digitally recorded and transcribed verbatim. Each interview lasted between one to two hours, thoroughly transcribed verbatim. Reiteration throughout interviews allowed for phenomenon of interest to be explored freely with spontaneity of discussion. An interview schedule was used for prompting as necessary around the topic of interest.

Epistemology

Methodologically this idiographic study was underpinned by phenomenology, hermeneutics, and symbolic interactionism (Larkin, Watts & Clifton, 2006). Thus the specific phenomenon under investigation sought individual experiences and their understanding of their experiences through reiterative exploration. In seeking to understand the relationship between humans and society, symbolic interactionism emphasises subjective meaning that individuals bring to their perceived reality of objects and events (Smith, 1996). Symbolic interactionism and double hermeneutics combine within interpretative phenomenology

methodologies to support researchers' attempts to make sense of participants striving to make sense of their own experiences concerning the phenomenon under investigation (Smith, Flowers & Larkin, 2009).

In this study, symbolic interactionism overlays the relationship of family members before and after the development of dementia as they seek to make sense of their relationship experiences within a wider context of dementia care within a medical system. Families are part of their own unit or group and will make sense of their own interactions differently. Consequently, this study sought to understand how individuals make meaning of their experience from both their social and internal world (Shinebourne, 2011).

Analytic Strategy

Methodologically this study utilized Interpretative Phenomenological Analysis (IPA) philosophically underpinned by phenomenology, hermeneutics and symbolic interactionism. IPA employs an eidetic method of searching for essential components and uniqueness of a phenomenon from the individual perspective (Brocki & Wearden, 2006; Spinelli, 2005). Specifically, from a psychological position (Larkin, Watts & Clifton, 2006), IPA aims to understand conscious experience of a person's interaction with their world (Larkin, Eatough & Osborne, 2011). Idiographic, inductive and interrogative, IPA is both empathic and meaning making in addition to suspicious and critically engaging, rather than hypothesis driven (Smith, 2011).

Specifically in this study, IPA is used to analyse experience of medical model dementia care from a family member's perspective. Transcribed data was systematically analysed according to IPA (Smith et al., 2009: see Table 2).

Insert Table 2

Credibility

Unlike nomothetic research, IPA seeks individual interpretations, authenticity of data and credibility through audit trails and robust discussion concerning thematic findings (Smith, Flowers, & Larkin, 2009). This is achieved through independent auditing whereby researchers individually provide rigorous succinct and transparent data analysis. The third author conducted and transcribed interviews. Independent auditing was then conducted by first and second authors, each completing a descriptive appraisal of data prior to discussion. Robust dialogue followed to determine consistent intersubjective interpretations which formed the depth and quality of this idiographic investigation.

Author's perspectives

Bracketing of one's personal biases and presuppositions is essential in IPA (Smith, Flowers & Larkin, 2009). The first author's clinical and research experience across the life span, specifically in trauma, spans over two decades. The second author is a clinical therapist and researcher with families exposed to complex trauma. The third author has 'lived' experience of caring for a family member with dementia, and now works in the field of dementia care as a clinical psychologist and researcher. In reflecting on the impact of these experiences to shape the analysis, we very much wanted the voices of families to be heard as an alternative to a disease perspective. Similarly, each author positions themselves as person-centred clinician recognising that medical models of care, though important, often undervalue, even nullify families' vast insight into the personality, fears, and psychosocial needs of a family member with dementia. Thus, of interest, was the experienced interface of systemic and family caring, and the benefits and detriments of both, in dementia care.

Results

One superordinate theme, *Navigating 'system' control*: overarches three sub-themes: *Connecting/Disconnecting*, *Windows Closing* and *Capacity for Sensation* (see Table 3).

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These themes explore transitions of families on dementia journeys from primary caretakers to passengers embarking on a system they perceive as oscillating between service orientation and a ‘warden’ mentality. They represent felt confusion and emotional challenges with which advocating and often guilty family members, struggle while trying to make sense of a large systemic medical environment. These themes encapsulate many parallel paths challenging participants’ ability to adapt given this speeding ‘roller coaster ride’ of dementia. On one hand changing and often convoluted communication patterns part of the later stages of dementia, tests their relational connectedness. On the other hand, remaining connected necessitates a commitment to this system, despite distress of acquiescence hierarchy. Unexpectedly, opportunities for growth surfaced. Finding capacity for connecting through sensory input (sensation) facilitates new language of communication for participants and loved one.

Insert Table 3

Connecting/Disconnecting

The medical model role in dementia family caregivers’ lives promotes uncertainty and apprehension. Worries diminish when the ‘system’ acknowledges residential care as the patient’s home and pursue development of rapport with patients, family and staff:

The DON (Director of Nursing) said ... this is their home and we’re here to help them ... They are amazing staff. There is a rapport that goes on between some of the staff and Dad (Lisa).

Confidence and sense of safety ease ever present vigilance in family members. Thus when quality care is perceived as consistent across patients and staff and a culture of service is sensed, they relax trusting their loved one is safe:

We know it’s not just because we’re there, because we see them doing it with the others as well ... we’re a lot happier ... they really cater to their needs (Cathy).

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Emotional digressions are never avoided. Irritation and defensiveness are easily prompted particularly in moments when staff's behaviour is interpreted as disrespect:

I said this is my father ... because everywhere we'd gone doctors would talk about Dad to us in front of him and he was sitting right there ... talk to Dad! Not just about him (Lisa)!

Unpredictable staff care is a key irritant for family members. Participants find this common among health caregivers within residential care. Vascilation between being able to trust or being ready to challenge persuasive manipulation becomes part of their daily lives. They are taken off guard when respectful communication occurs:

Dr ... was concerned. He communicated with Dad too ... without coaxing (Dawn).

Unable to make sense of who was in charge or trust their own judgement in a crisis, many responses to these encounters leave them feeling isolated and inept:

I sent for the ambulance, and they took him into the hospital and unfortunately, that's when they sedated him and I think that didn't do him any good at all (Shirley).

Trying to make sense of this variability of medical model care, participants dichotomise care as either individualised care or authoritarian warden care. This variability is contagious and plays havoc with their own role and sense of responsibility towards their loved one. Connection/disconnection imbues confusion about where, how and from whom to seek or provide help. They are on high alert, uncertain of when the next tussle will occur within a vast impersonal system that disregards their own autonomy:

I'd lost him ... I felt that they'd taken him and changed him ... and I had no say in the matter (Betty).

This connection/disconnection continues experienced as unstable footing for maintaining authority over care of their loved one within a powerful system. Connection occurs momentarily when sensing inclusion in decision making. In response they willingly extend the hand of trust only to be thwarted, producing a staggering sense of disconnection,

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throwing them off balance. Such moments occur when medication changes are introduced without consultation. Perceptions of a hostile nation where the family visits, framed in an overbearing and authoritative system begets distrust:

I was being very positive, every time I'd visit Dad, I'd say Dad it's going to be OK, the medication will stabilise ... let's just trust the doctors, I don't know how many times I said that, let's just trust the doctors, they know what they're doing, and then it got to the point where after how many doctors and how many changes of medication he (and we) really did not trust the doctors anymore (Lisa).

Confounding their feelings of hypervigilance around responsibility is pressure from the family member with dementia, to continue as advocate. These strong family bonds and unspoken expectations of protection, responsibility and trust often cause chaos and doubt in the moral consciences of visiting family members. 'Doing' all the right things isn't enough. Surreptitiously, connection with the loved one with dementia is slipping away:

And he was trusting, us! That we knew. You know, that we were advocating for him. And we were. We really were. But...we were watching Dad slip away and he couldn't ... he could not verbalise with us (Lisa).

Feelings of despair feed distrust and anger with 'doctors'. It becomes an 'us' against 'them' as family members determinedly strive for holistic care. Shrewdly, there are moments of insightfulness where they recognise the need for all family members to be on the same team despite historic fractures:

I don't trust doctors! If you go to hospital, you make sure you've got a pack, a team of people who are there to advocate for you, and a team of people who will get things moving ... the psychiatrist, well she puts her medication into Dad ... but as a whole person, they don't treat people as a whole person. They treat people for that specific area in the body! A pill for that ill (Lisa)!

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Inconsistency, variability of care, lack of inclusiveness in care vexes participants and increases their sense of powerlessness. Intrinsically, courage and strength to confront this hierarchical system that is perceived as process focused rather than inclusive, is symbolically a battle needing to be fought:

I wasn't asking for anything special ... I was asking for consideration for my husband, and I wasn't getting it ... I felt that my back was against the wall ... and I had to fight (Joan).

Hypervigilance and suspicion are common responses when exclusion of their opinion is blatant and tactical. Immediately they recoil from those moments of inappropriate dictating and threat, even bullying:

That doctor said she would have him admitted, and ... he would be an involuntary patient...I'm a doctor and if you don't decide what to do with him, then I'll have him interred as an involuntary patient and you'll have no say in the matter whatsoever, so what do you think of that (Betty)?

Windows Closing

Like a wound that bore no external scars, vicarious exposure to behaviors, cognitions and emotions from a loved one with dementia, were traumatic:

It's really hard to deal with ... It's very stressful. We've been through a really stressful period ... He got very suspicious of me ... it was pretty traumatic (Joan).

Moreover coercive abdication of care to the medical model, “*was traumatic ... a massive stress*”. Once in permanent residential care, participants experience the system as a blunt, physical force that inserts a point of authoritative threat cumulative upon loss of environment and disorientation in the loved one. Guilt and loss of advocacy for family members oscillates with their sense of being supportive. They encounter further traumatic changes of loss and separation:

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They (staff) do not realise how big a trauma it is for that person that's in the home to go out to another place, you know ... He was really, really stressed out ... Believe you me it was trauma, trauma, trauma because he was out of his environment ... taking them out of their environment is one of the hardest things you will ever do (Shirley).

Abdication of care intrinsically drives tremendous sense of grief and wrongdoing in relinquishing care. In essence participants feel they have failed in their relationship with their loved one and in their role as carer:

I blame myself a lot for initially sending him into the hospital. I feel very guilty. I could have kept him a bit longer ... well you certainly feel as if you've failed (Betty).

Unable to be extinguished, guilt continues to intensify and generalise to broader aspects of self. They question role in love, duty, advocacy and loss. They experienced intrusion of revolving doubt:

And I suppose, probably a bit of a guilt thing ... you think ... do I have a spare afternoon, but I don't really want to go all the way down there if I'm going to be there for five minutes because she's in one of her angry moods where you walk in and then you turn around ... that was a bit of a waste of a trip (Megan).

Interactions, once enjoyed now become a journey of endurance as they zigzag between guilt whilst incurring anger and agitation from their loved one. The progress through severe stage of dementia opens further doors of the unexpected:

I said something ... he jumped up and got really, really aggressive with me (Joan).

The progress through later stage dementia is a journey of closing windows both for the family members and for those with dementia. Families often question the point of visiting. For many, duty is borne alongside grief, abuse, and vicarious distress that hover hand in hand with those episodes of primary exposure to traumatic events. The lost opportunities to protect and re-establish dignity visibly confronts them as dementia advances:

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The environment ... it was all foreign ... it'd be like being lost, and not knowing where you are ... She just sat there with her fingers in her ears, and didn't eat (Kayla).

With loss of cognitive awareness, ability to identify self, and unpredictable changes in behaviour as dementia advances, loss of hope, loss of purpose, and loss of connectiveness are windows closing for the family members:

Well, it must be just part of the illness ... I think there are windows. I call them windows. Sometimes she is; other times she's not. There used to be bigger windows.

This is how I explain it. Now they're tinier, and they're rarer (Cathy).

Finding the capacity for sensation

Sensation and stimulation become a conduit for remaining connected. Family members alert for alternative stimulation continue assisting their loved one with dementia to maintain some sense of purpose;

I believe you have got to do more things and get them out and do more to stimulate their minds ... Just because they are declining does not mean they should have no purpose to their day (Cathy).

Rhythmic communication through movement becomes a type of morse code assisting participants as well as their loved one. There is found understanding through recognising the power of sensation:

It's the simple things like they (staff) throw the ball to him and that type of thing and they play with that for some time and he seems to communicate with that, and he communicates with music and dancing (Dawn).

For example comparable to an engine warming, walking improves interaction allowing family members to enjoy the time spent with their loved one. Remaining conscious to the opportunities these small actions provide, nudges the window open a little and gives respite from hopelessness and futility:

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I'll say ... Would you like to go for a walk ... and that seems to start you know ... he kind of thinks ... Oh well I'll go for a walk with her ... and things just kind of get better from there on (Diane).

They have found a way of connecting, joining in rhythmic activities for finding a pathway to interaction:

You try ... dance, taking him for a walk ... If you ... haven't got any communication well you're just sitting there ... he dances ... he sings and that's communication. It's not talking, because he doesn't understand (Betty).

Sensation appears to be the vehicle that allows acceptance, relaxation, and a willingness to 'go for the ride'. Ready willing and able to pursue a sense of presence in the later stages of dementia brings amusement to family members amongst the difficulty of being unknown:

I kneel in front of him so that I'm face to face...you've got to make them concentrate ... Look at me ... Look at me ... Look at me ... And I talk to him ... You know me don't you? And ... sometimes he will say ... yes I know you ... and I think ... you bugger you don't know who I am (Joan).

The ability to be open to alternative ways of being in a relationship encouraged its own thrills and joy. There is an unknown pathway every day on their journey with dementia. Tactile sensation allows them ways of expressing what words can no longer translate, encouraging familiar historical relatedness:

When he kisses me that's one way of expressing himself, and sometimes when I say that I'm going, and he'll hold onto my hand. (I wonder) So does he really want me to go or does he want me to stay...(He holds hand tightly) only when I try to pull it away. Although sometimes if he's, he's had his eyes closed and he suddenly wakes up, he'll sort of grip then (Shirley).

By being flexible, new and previously unexpected ways of engaging through tactile sensory awareness bring unexpected joy for the family member as they witness retained sensory awareness being expressed in their loved one with severe dementia:

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I don't have a plan. I take it day by day ... I just talk to him. I talk to him. I cuddle him. Hold his hand ... I think touch is a big thing (Dawn).

Stoic determination of family members to assist their loved one parallels an openness to being unknown and a determination not to be forgotten:

I don't think that I would get too upset if he didn't recognise me ... but on the other hand, I'm determined he's not going to forget me easily (Shirley).

Time becomes unimportant except for astute timekeeping of those moments of connectedness where significant and momentary interaction can occur:

After 10 minutes he knows who I am ... I think what goes on in their head is this ... who is this ... Now I know who this is. I'm dammed if I can figure it out ... and I make sure he knows, I whisper in his ear in a loud voice ... I think it takes him at least 10 minutes to realise that I'm there and that I'm someone he knows ... You know how they say wait ask a question and wait seven seconds, well I think I come in and I've got to wait at least 10 minutes (Joan).

The roller coaster ride spoken of with angst and uncertainty during the earlier reflections and interpretations observably shifts in meaning to one of alert advocate, yet competent explorer ready for the next part of the journey:

We're on the flat part of the roller coaster ... You don't know what's around the corner and you're just going to have to wait and see. It's ... a matter of just sitting back and just being there for her (Cathy).

Discussion

Importantly this study highlights participants' interpreted experiences of navigating a systemic pathway of dementia care framed within the medical model. Results indicate one superordinate theme, *Navigating 'system' control*, overarched three subordinate themes: *Connecting/Disconnecting*, *Windows Closing* and *Capacity for Sensation*. The overarching theme, *System control* represents the participants voiced difficulty in navigating the medical

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model of dementia care. Their perceptions are of a complex maze that is full of contradictions; is threatening yet at times comforting; is authoritarian yet often humane. Vigilance became the hallmark for taking care of self and advocating for a family member with dementia as they manoeuvred a system of care that imposes its uninvited authority at will. *Connection/disconnection* described the enduring struggle to remain included in the caregiving role. Vicarious distress and at times primary trauma were experienced and recognised as *windows closing*. Despite distress, psychological wellbeing and growth were possible for these participants through a *capacity for sensation*. As such, redefining of relational connectedness with the family member with dementia became an effortful consciousness of communication that transitioned primarily to sensory exchange.

This is one of the few known studies of family caregivers' experience of a medical model of residential dementia care for those with severe dementia. Therefore participants have provided a black box of knowledge underscoring difficulties of navigating a medical model approach to dementia care from their viewpoint. For them, the medical model of care was either individualised or authoritarian. Depending on the facility's systemic culture of providing care to the family member with dementia, it was either specific to that person's individual needs and wants, or guided by a strictly medicalised model of care in which diagnosis informed and directed a one-size fits all approach. Relief from their ever present angst was intermittent and came when the facility and staff were oriented towards viewing residential care as the patient's home, whilst also seeking relationship with the family. Conversely, and in line with systemic trauma theory, this was part of a see-saw of responses where stress and defensiveness returned when family caregivers were rendered powerless from disrespectful and dismissive responses from staff.

Participants spoke of a continuing confusion, and confronting challenges as they relinquished primary care. Trust and inclusion became unpredictable expectations of a

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hierarchical and powerful system, and most commonly, an adversarial position was perceived by family members as a necessary tool to maintain that advocacy. Redefining their relational connectedness with the family member with dementia became an effortful consciousness of communication that transitioned primarily to sensory exchange.

These participants felt unable to trust system care givers, experiencing care and service to their loved one as inconsistent and unpredictable. Similarly, isolation and variability of the system impacted their own relationship with their loved one. Hypervigilance towards an impersonal system formed an unstable foundation on which to collaboratively mediate the care of their loved one. Medication changes, without consultation were found to cause the most disconnection from the care inclusion process. Family members desperately tried to maintain their role as patient advocate, yet the medical model was viewed as facilitating opposition rather than collaboration, symbolically viewed as a hierarchical giant with which the families were forced to battle.

Constructivist Social Development Theory (CSDT: Saakvitne, Gamble, Pearlman, & Tabor, 2000) speaks to both the negative and positive actions that are part of trauma and its recovery. It focuses on hope, connection, collaboration, respect and empowerment and aligns with other trauma frameworks that encourage ‘feeling skills’ and trauma informed care (Briere, 2004). Though these family caregivers had difficulties managing the family caregiving role in dementia, frequently they were able to redefine their trauma and grief with new and creative ways of remaining connected. Similar to CSDT, grief and distress related to traumatic events facilitated hope, and efforts to remain connected, while collaboratively advocating for respect and empowerment for their loved one.

Consistent with systemic trauma theory, guilt, questioning of their role, not fully honouring duty, and doubt, overwhelmed these participants at times. They spoke of feeling a sense of wrongdoing at not being able to provide the necessary care and as such struggled to

make sense of their grief, loss sense of failure at relinquishing care (Large & Slinger, 2015; Evans & Emmanuel, 2014; Hege Forsund, Skovdahl, Kiik, & Ytrehus, 2014). They spoke of a sense of wrongdoing that appeared to trigger guilt, questioning of their role, the duty they had towards caring, and doubt. Additionally, anger and agitation directed at them, sometimes abusively by their loved one, was a constant challenge to their sense making in light of significant amounts of personal sacrifice made by family members.

Family caregivers' perspectives suggest they experienced vicarious distress and at times primary trauma from the impact of confronting behaviours, cognitions, and emotions of a loved one with dementia, and events surrounding the relinquishment of care. Vicarious exposure to dementia in a loved one was spoken of as an 'internal wound'. They experienced the medical model of care as coercive sensing an expectation that they should collude with staff. Similar to betrayal trauma, navigating a powerful and authoritarian system became for some, a journey of protection for self and loved ones. Such primary exposure to traumatic situations has until now been under-acknowledged or disregarded. With a lens on both primary and secondary trauma, future research could further explore the impact, both positive and negative, from the plethora of potentially traumatic events likely to be experienced by family members. Similarly, models of growth offer the opportunity to assist families to reappraise the dementia pathway as one that is opportune for psychological growth despite distress. As such, dementia care models inclusive of family members could adopt frameworks of growth coexisting with support for traumatic distress and grief.

Several findings from this current study concur with previous research that described residential dementia care as a systemic giant maze that must be navigated to survive (Peel & Harding, 2014; Nowell, Thornton, & Simpson, 2011). Overwhelming guilt and grief at the abdication of care has been similarly recognised and emphasised (Large & Slinger, 2015). Positively, and of interest to this study, stimulation and tactile involvement have also been

acknowledged as providing relief from the intrepid dementia decline (Nicholls, Chang, Johnson, & Edenborough, 2013). Of interest, and similar to very recent findings, traumatic distress and growth were observed concurrently. For example despite the distress of the dementia journey, psychological growth was found possible if family members could achieve connection and retain engagement through communication with their love one through sensory awareness (Walmsley & McCormack, 2014a; 2014b; Walmsley & McCormack, 2015). This has implications for informing future interventions to facilitate creative communication through sensory awareness and exchange.

Recent studies have shown that caregivers, be they professional caregivers or family members, are positioned to redefine their vicarious distress as opportunities for psychological growth (McCormack & Adams, 2015; McCormack & Joseph, 2014). For families of this study, family caregivers are recognised as the unpaid caregivers in dementia and many spoke of the dichotomous experiences of distress and growth during their interviews. They experienced the confines of institutionalised dementia care as adding another layer of distress to the family similar to other studies reliant on institutional care for safety (McCormack & Joseph, 2014). That same sense of threat to personal integrity, in the shadow of a large and powerful hierarchical system was identified by family caregivers as directly related to the systemic medical model of care.

The impact on relatives when a loved one is emotionally distant and unavailable due to psychological distress is now well described (Dekel, Solomon & Bleich, 2005; Figley, 1998; Harkness & Zador, 2001; Lyons, 2001; McCormack & Joseph, 2012). These participants spoke of feeling traumatised when threatened by erratic behaviours inclusive of psychotic episodes and regression of emotional interaction from their loved one. Redefining authenticity and aligning with domains of psychological growth appear to have been conduits

in this study for meaning making and acceptance of the participants' decision to relinquish care.

There is early evidence to suggest that sensory awareness uniquely assists in communication with later stage dementia (Walmsley & McCormack, 2014a). As such sensation and stimulation may well assist those with dementia to have purpose, and subsequently improve wellbeing for family caregivers. Similarly movement can be transpired into a form of rhythmic communication and physical activity. Tactile tasks have been used as a method of therapy to find understanding between patient and person-centred approaches by staff (Coaten & Newman-Bluestein, 2013) or family. The current results identify examples of dementia staff and family caregivers achieving a shared understanding with a dementia patient through the recognition of the power of sensation. Walking also offered the opportunity to stay connected with a loved one with dementia in this study. In other studies relationship was reignited via familiar historical relatedness (Walmsley & McCormack, 2015) offering partners the opportunity to still seek a sense of belonging and reciprocity despite considerable cognitive decline and separation (Hege Forsund, Skovdahl, Kiik, & Ytrehus, 2014).

Though the possibility of psychological growth out of the adversity of dementia is as yet, poorly researched, psychological growth in conjunction with distress was observed in this study. Finding humour amongst the difficulty of being unknown allowed family members to pursue a sense of presence in the life of their loved one. Remaining flexible and open to alternate ways of connecting through sensation brought unexpected joy. Time was not a priority, except when the ability to be present became the timekeeper of moments.

Limitations

Whilst qualitative research addresses the uniqueness of an individual's experience generalisations and cause and effect do not apply. Furthermore, idiographic individual

experiences can be potentially subjective, intuitive and impressionistic that without rigorous auditing can limit important interpretations (Pringle, Drummond, McLafferty & Hendry, 2011). By investigating individual unique experiences across converse and diverse themes, an interpretative phenomenological analysis can offer useful insight into an often unknown or under researched phenomenon (Reid, Flowers & Larkin, 2005).

Small sample sizes are argued to be a limitation in qualitative investigation, yet small sample sizes allow for the volume of data necessary for rich depth of analysis. Although, IPA has been criticised for being constrained by its philosophical and theoretical roots (Braun & Clarke, 2006), it is the very theoretical roots of IPA that adds depth and purpose in comparison to other methods of qualitative inquiry (Shinebourne, 2011). It is conceded that IPA is a rigorous method of research analysis with transparent core philosophical features which forms the basis for this research (Smith, 2011).

Conclusion

This study highlights that for these participants, navigating a medical model of *system control* in dementia care was at times threatening, brought additional distress, and added to guilt and grief on their dementia journey. Care was found to be individualised or authoritarian, dependent on the culture of the particular residential home and their interpretation of systemic care. When care was consistently service oriented and facilitated relationship within the family, the journey was more bearable. Conversely, family caregivers became emotionally defensive when staff disrespected the dementia family member. Desperately trying to continue as patient advocate, the medical model was perceived as an opponent rather than ally. Despite feeling traumatised, and plagued by grief, guilt and sense of failure at relinquishing care, family caregivers found avenues for psychological growth. Even though windows of connection were closing, connection and communication were possible with severe dementia via unique ways that included sensory awareness.

DEMENTIA, FAMILIES AND THE MEDICAL MODEL

Implications for practice include acknowledgement that the dementia family caregiver may experience primary and/or vicarious distress whilst navigating the medical model, witnessing threat to loved one or others, and struggle with feelings of guilt, stigma, loss and grief. Psychological support is not always recognised as a necessary part of dementia care yet psychologists have the opportunity, if included in the care programs, to provide support and promote psychological wellbeing despite the ongoing distress of the dementia journey. Family care programs inclusive of psychological input for both family caregivers and those with dementia are encouraged to include creative communication including sensory awareness and exchange.

Conflict of Interest:

None

Description of Authors' roles:

The first author supervised this project, and jointly developed the design with author three. Both first and second authors were the independent auditors who robustly debated the final thematic analysis and write-up of the results and paper. The third author recruited the participants, conducted the interviews and transcribed the data.

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Transcript Extract Notations

— A pause in speech.

... Removal of nonessential material.

Table 1. Participant Demographics

Resident/Age Severe Stage Dementia	Family Carer/Age/Relationship	Years of Caring
Esther (80)	Cathy (57) Daughter (primary carer)	5 years
Esther (80)	Megan (27) Granddaughter	
	Diane (53) Daughter, sister to Cathy (primary carer)	5 years
	Kayla (26) Granddaughter	
Tom (84)	Shirley (80) Wife (primary carer)	4 years
Ross (72)	Dawn (71) Wife (primary carer)	4 years
	Lisa (47) Daughter	
Ron (84)	Betty (76) Wife (primary carer)	5 years
Don (70)	Joan (70) Wife (primary carer)	4 years

Table 2. Systematic Data Analysis (Smith, Flowers and Larkin, 2009).

Step	Process
1. Initial note taking.	Examination of the semantic and language identifies initial descriptions of experience and further reflection.
2. Developing emergent themes	Identification of emergent themes is developed from the interrelationships, connections and patterns.
3. Quality	Auditing through simultaneous and independent checking maintains quality control. First author assessment of authenticity and thematic representation brackets out any biases and presuppositions from the second author's interpretation. Emergent themes are arrived at via robust author discussion and analysis with strict adherence to the philosophical principles of IPA. Whilst multiple genuine themes are possible a detailed audit trail negates the included convergent and divergent themes through a credible, and systematic analysis of the phenomenon.
4. Searching for connections across	Conceptualization of the emergent themes

emergent themes	assemble superordinate clustered themes that are mapped via graphical tabling.
5. Moving to the next case	Each transcript undergoes the previous step.
6. Looking for patterns across cases	The tables of superordinate themes and the initial emergent themes from each transcript are compared for connections and patterns. The collective connections are then tabled and the superordinate themes are nested within to capture participant's most important perception.

Table 3. Overarching Superordinate Theme: Navigating 'system control'

Subordinate Themes
<ul style="list-style-type: none"> • Connecting/Disconnecting • Windows Closing • Capacity for Sensation

Appendix 1. Interview schedule for family members

1. We are interested in your own experience of dementia and how you interpret its impact on your life both positively and negatively?
 - a. Your thoughts, feelings, priorities that may have changed through this experience;
 - b. Your world views that may have changed;
 - c. Impact on your relationships and communication skills;
 - d. How you make sense of being caught up in these human dynamics;
 - e. How you make sense of your spiritual beliefs, if any; and
 - f. How you see your life going forward from these experiences.
2. Can you please also provide the following demographic information?
 - a. Your age; and
 - b. The length of time you have been caring for your family member with dementia.