

**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.

9th December 2013

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

ACKNOWLEDGEMENTS

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.

I was also very fortunate to have the enduring support of my family, friends and colleagues. It would have been impossible to sustain this project without their faith in my abilities and tolerance for the highs and lows which seemed to characterise my PhD candidature. To my husband Stuart, and our son Robert, I owe the deepest gratitude for seeing in me that which I could not, for providing unconditional love and respect, and showing extraordinary patience. I thank you for understanding my absences from family life, for supporting me through the tougher times and having faith that I would make it to the end. To Karin Calford, a true friend, I owe heartfelt thanks for years of listening, support and caring. Finally I would like to acknowledge and thank my study supervisors, Professor Isabel Higgins and Professor Dianna Keatinge, for their guidance and for keeping me focused, thoughtful and true to the experiences shared by the women in the study. In particular, I would like to thank Professor Higgins for her guidance to the phenomenological way.

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

- Day, J., Higgins, I., & Keatinge, D. (2011). Orientation strategies during delirium: Are they helpful? *Journal of Clinical Nursing*, 20(23-24), 3285-3294. doi: 10.1111/j.1365-2702.2011.03849.x.
- Day, J., Higgins, I., & Koch, T. (2009b). The process of practice redesign in delirium care for hospitalised older people: A participatory action research study. *International Journal of Nursing Studies*, 46(1), 12-21. doi: 10.1016/j.ijnurstu.2008.08.013.
- Li, I., Giles, M., Dumont, F., Day, J., & Higgins, I. (2009). The uptake and utility of a protocol for delirium prevention: An evaluation study. *HNE Handover: For Nurses and Midwives*, 2(1), 7-11.
- Day, J., Higgins, I., & Koch, T. (2008). Delirium and older people: What are the constraints to best practice in acute care. *International Journal of Older People Nursing*, 3(3), 170-177. doi: 10.1111/j.1748-3743.2008.00115.x.

Book Chapters

- Armitage, D., Conway, J., Day, J., Hewett, J., Higgins, I., Hullick, C. & Maslin-Prothero, S. (2013). Communicating with older people. In Levett-Jones, T. (Ed.), *Critical conversations for patient safety: An essential guide for healthcare professionals* (pp.114-124). Sydney; Pearson Australia.
- Day, J., Higgins, I., & Koch, T. (2009). Delirium in older people in acute care. In R. Nay & S. Garratt (Eds.), *Older people: Issues and innovations in care* (3rd ed., pp. 244-260). Sydney: Elsevier.

Conference Posters

- Day, J., Higgins, I., & Keatinge, D. (2013). *Family member experiences during an older loved one's delirium*. Poster presentation at the 12th Emerging Researchers in Ageing Conference, November 2013, Sydney.
- Day, J., Higgins, I., & Keatinge, D. (2010). *The lived experience of family members who visit a hospitalised older person when the older person has delirium*. Poster presentation at the 9th Emerging Researchers in Ageing Conference, October 2010, Newcastle. **(Best Poster Presentation Award)**

TABLE OF CONTENTS

ABSTRACT	7
KEY	9
CHAPTER 1: STUDY INTRODUCTION	11
Chapter Introduction.....	12
Why Explore the Experiences of Family Members?	13
Study Purpose and Research Question	14
Understanding the Phenomenon Being Studied	16
Delirium: Definition, Characteristics and Types.....	16
Differentiating Delirium, Dementia and Depression	19
Family Member Involvement in Care	20
Family Member Needs and Support Interventions	22
Delirium: Word Origins and Meanings	24
Delirium: A Common Condition in Unwell Older People	28
Study Context	36
Completing the Study	39
Thesis Organisation	40
Review and Summary	41
CHAPTER 2: NARRATIVE LITERATURE REVIEW-EXPERIENCES OF DELIRIUM AND LOSING A LOVED ONE’S SELF	43
Chapter Introduction.....	44
Experiences of Delirium	44
Older Peoples’ Experiences of Delirium	46
Nurses’ Experiences During Older Person Delirium	54
Family Members’ Experiences During Older Person Delirium	61
Family Members of Older People, Advanced Cancer and Palliative Care Patients....	63
Limitations in Current Knowledge	69
Family Members’ Experiences: Older People and ADRD	70
Experiences of Losing a Loved One’s Self During ADRD	71
Theoretical Understandings: Loss of a Loved One’s Self	78
Conceptualisations of Losing a Loved One’s Self: Absence and Loss	80
Summary and Conclusion	87
CHAPTER 3: GUIDING APPROACH	91
Chapter Introduction.....	92
Selecting the Guiding Approach	92
The Qualitative Research Paradigm and Phenomenology	93
Phenomenology and Existential Phenomenology	95
The Philosophies of Sartre and Merleau-Ponty	98
Returning to Human Experience of Things Themselves	101
Consciousness and Intentionality	101
Perception.....	103
Embodiment and Relationality.....	106
To be Human is to be Situated in the World.....	114
Searching for Meaning.....	118
Expectation, Lack and Existential Absence.....	122
Review and Summary	125

CHAPTER 4: STUDY DESIGN AND METHODS.....	127
Chapter Introduction.....	128
Trustworthiness and Applying Existential Phenomenology.....	128
Trustworthiness.....	128
Phenomenological Orientation.....	130
Focusing on the Phenomenon for the Study.....	131
Aim of the Study.....	133
Assumptions and Pre-understandings.....	133
Investigating Experience as it is Lived.....	137
Collecting Family Member Experiences.....	139
Collecting Other Lived Experience Sources.....	157
Analysis of Interpretive Interaction.....	164
Writing the Phenomenological Narrative.....	167
Writing a Narrative on the Meaning of the Study.....	170
Review and Summary.....	170
CHAPTER 5: FINDINGS PROLOGUE.....	173
Chapter Introduction.....	174
The Women Who Participated in the Study.....	174
Participant Biographies.....	177
Ann (Participant 1).....	177
Sally (Participant 2).....	179
Lyn (Participant 3).....	180
Cathy (Participant 4).....	182
Sharon (Participant 5) and May (Participant 6).....	183
Beth (Participant 7).....	184
Janine (Participant 8).....	185
Pat (Participant 9).....	186
Brooke (Participant 10).....	188
Betty (Participant 11).....	189
Gemma (Participant 12).....	190
Carmel (Participant 13).....	191
Iris (Participant 14).....	192
Review and Summary.....	193
CHAPTER 6: FINDINGS.....	195
Chapter Introduction.....	196
The Essence.....	197
Living the Fragility of a Loved One's Presence (<i>Theme</i>).....	198
Facing a Loved One's Existential Absence (<i>Sub-theme</i>).....	200
Living With a Stranger (<i>Sub-theme</i>).....	204
Living Life Holding On (<i>Theme</i>).....	210
Waiting for a Loved One (<i>Sub-theme</i>).....	211
In the Dark (<i>Sub-theme</i>).....	216
On the Fringe but Centre Stage (<i>Sub-theme</i>).....	219
On Thin Ice (<i>Sub-theme</i>).....	226
Keeping Secrets (<i>Sub-theme</i>).....	228
Review and Summary.....	230
CHAPTER 7: DISCUSSION AND CONCLUSIONS.....	233
Chapter Introduction.....	234
The Existential Nature of Delirium.....	235
Loss of a Loved One's Self During Delirium: Past Findings.....	245
Loss of a Loved One's Self During Delirium and Current Theory.....	247
Practice Implications.....	253
Trustworthiness and Study Limitations.....	259

Future Research	263
Conclusion	265
REFERENCES	267
APPENDIX A: REVIEWED LITERATURE	309
APPENDIX B: INTERMEDIARY RECRUITMENT INFORMATION PACK	319
APPENDIX C: RESEARCH REGISTER RECRUITMENT INFORMATION	337
APPENDIX D: INTERVIEW SCHEDULE.....	345
APPENDIX E: TRANSCRIBER UNDERTAKING	351
APPENDIX F: HUMAN RESEARCH ETHICS APPROVALS	353
APPENDIX G: DATA ANALYSIS ILLUSTRATIONS	369

TABLE OF FIGURES

Figure 1: Data Sources	138
Figure 2: Wordle™: Women's Expressions	159
Figure 3: Essence, Themes And Sub-themes	199

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.
<i>Indented italic text</i>	Long participant transcript excerpts.
<i>“Italicised text”</i>	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 – <i>pnumber</i>)	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.
<i>pnumber/number</i>	Excerpts that continue across transcript paragraphs.

