An interpretative phenomenological investigation of dementia from the perspective of families and system caregivers: Stigma, traumatic loss, psychological growth, and Relational Social Engagement (RSE).

Bruce Walmsley
BCom, G/PGDipPsych, MClinPsych

Thesis submitted to the University of Newcastle for the degree of Doctor of Philosophy (Psychology-Science)

December 2016
Statement of originality

The 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.

Statement of collaboration

I hereby certify that the work embodied in this thesis has been done in collaboration with other researchers. I have included as part of the thesis a statement clearly outlining the extent of collaboration, with whom and under what circumstances.

Statement of authorship

I hereby certify that the work embodied in this thesis contains a published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written statement, endorsed by my supervisor, attesting to my contribution to the joint publication/s/scholarly work.

This thesis was completed under the primary supervision of Dr Lynne McCormack PhD, and secondary supervision of Dr Sean Halpin PhD.

Bruce Walmsley ................................................................. Date: ..................................................
PhD Candidate

Dr Lynne McCormack .......................................................... Date: .............................................
Primary Supervisor
Acknowledgements

My great appreciation goes to the health care managers and families who participated in this research. Thank you for generously offering your time to share your experiences of dementia, especially through video-recorded observations. I gratefully thank the directors of aged care services at the participating care homes for helping with participant recruitment. Your support has helped make this research possible.

Similarly, this research would not have been possible without the support and guidance of my primary supervisor Dr Lynne McCormack. My very special thanks go to Lynne for her availability and willingness to read, edit, and critically discuss my work. Her enthusiasm and good humour has been steadfast. I greatly appreciate Lynne's hard work during our meetings and behind the scenes. I am also grateful to my secondary supervisor Dr Sean Halpin for his advice and encouragement. Thank you also to the anonymous journal reviewers for your comprehensive feedback that has enhanced my skills in writing for publication.

I also thank the following people: Valerie Rendle, for helping me discover new perspectives; Dr Gaye Gleeson, for her inspiring lectures in geropsychology at Western Sydney University; and in particular, Dr Mike Bird for his research advice, encouragement and offer of clinical placement with the Specialist Mental Health Services for Older People in Queanbeyan, NSW.

My special thanks go to my family and friends for their love and support. In particular, thank you to Mum and Dad, Aunty Mary, Andy, Carol, Margie, and my fabulous nieces and nephews. For her desk side companionship and patience, thank you to my dog Ruby. And of course, a huge thank you to my wonderful circle of mates. It has been an adventurous change of career. Thank you for being there.
DEDICATION

For Mum and Dad

Without your love, support, belief, and encouragement

this PhD and my career in clinical psychology

would not have been possible.
Publication Status of Chapters

The following manuscripts, developed from the research described in this thesis, are published or in preparation for submission. For all manuscripts, the PhD candidate recruited the participants, collected, and transcribed the data sets. Similarly, for all manuscripts, apart from McCormack, Tillock and Walmsley (2016), the PhD candidate and primary supervisor jointly developed the design, were independent auditors, and co-authors. For McCormack, Tillock and Walmsley, the first and second author conducted the independent auditing. All contributed to authoring.


Chapter 7  Walmsley, B. D., & McCormack, L. (To be submitted). Trauma and growth: The
impact of dementia care pathways on family carers.

Walmsley, B. D., & McCormack, L. (To be submitted). Trauma and growth in families, despite the relational and social impacts of living with dementia.

McCormack, L., Tillock, K., & Walmsley, B. D. (2016). Holding on while letting go: Trauma and growth on the pathway of dementia care in families. *Aging & Mental Health, 1–10*. Online 16th February:

http://dx.doi.org/ 10.1080/13607863.2016.1146872
# Table of Contents

Statement of originality 1
Statement of collaboration 1
Statement of authorship 1
Acknowledgements 2
DEDICATION 3
Publication Status of Chapters 4
Abstract 11
List of Tables 16
List of Figures 17
Glossary of Terms and Abbreviations 18
PREFACE Personal Journey 19

## CHAPTER 1 Aims, Objectives, and Thesis Map 27

### 1.0 Introduction 27

### 1.1 Aims and objectives 27

#### 1.1.1 Research considerations 29

### 1.2 Analytical strategy 31

#### 1.2.1 Interpretative Phenomenological Analysis 33

#### 1.2.2 Thematic Analysis 34

### 1.3 Chapter map 36

### 1.4 Chapter close 37

## CHAPTER 2 Literature Review 38

### 2.0 Introduction 38

### Section 1 38

### 2.1 Setting the scene 38

### 2.2 A complex condition 41

#### 2.2.1 Underlying neuropathology 45

#### 2.2.2 Influence of biopsychosocial factors 45

#### 2.2.3 Functional changes in dementia 49

#### 2.2.4 Stigma versus living well 59

### 2.3 Dementia treatments 64

#### 2.3.1 Pharmacological interventions 64

#### 2.3.2 Psychosocial interventions 65

### 2.4 Impacts on health care staff 69

#### 2.4.1 Systemic impacts on health care staff 69
2.5 Impacts on families
  2.5.1 Systemic impacts on families
  2.5.2 Relational impacts on families

Section 2:

2.6 The historical narrative
  2.6.1 Dementia care, from antiquity to the Victorians
  2.6.2 Dementia care at the turn of the 20th century
  2.6.3 Contemporary models of dementia care

Section 3:

2.7 Constructs and theoretical underpinnings of this thesis
  2.7.1 Levels of Awareness framework
  2.7.2 Social Positioning Theory
  2.7.3 Theories related to caregiving adversity and its impact

2.8 Chapter close

CHAPTER 3 Methodology

3.0 Introduction

Section 1:

3.1 Ontological concerns
  3.1.1 Objectivist ontology
  3.1.2 Post-objectivist ontology
  3.1.3 Interpretivist ontology
  3.1.4 Dynamic between objectivism and interpretivism
  3.1.5 Critical relativism
  3.1.6 Critical realism

Section 2:

3.2 Epistemological and philosophical concerns
  3.2.1 Phenomenology and transcending knowledge
  3.2.2 Phenomenology and interpretation
  3.2.3 Phenomenology and hermeneutic enquiry
  3.2.4 Hermeneutic circles
  3.2.5 Contextual and co-constructed meaning
  3.2.6 Hermeneutic breakdowns

Section 3:

3.3 Methodology and Method
  3.3.1 Participants
  3.3.2 Data collection and analytic procedures
7.0 Introduction

7.1 Method
   7.1.1 Participants
   7.1.2 Procedure

7.2 Results and Analysis
   7.2.1 Results and analysis regarding families and the care system
   7.2.2 Results and analysis regarding familial relationships

7.3 Discussion
   7.3.1 Conclusions and recommendations

7.4 Chapter close

CHAPTER 8 Critical Reflections

8.0 Introduction

8.1 Personal reflections on using qualitative methodology
   8.1.1 Bracketing biases and preconceptions
   8.1.2 Using interviews to collect data
   8.1.3 The making of video recorded observations
   8.1.4 Relational dynamics
   8.1.5 Non-reciprocal, person-centred stance

8.2 Study strengths and weaknesses

Chapter close

CHAPTER 9 Thesis Conclusions and Implications

9.0 Introduction

9.1 Key research findings of this thesis
   9.1.1 Informed by complementary pilot studies
   9.1.2 Supporting perspectives of health care managers
   9.1.3 Close-up perspectives of family members with dementia
   9.1.4 Contextual perspectives of family caregivers

9.2 Research conclusions

9.3 Future research

9.4 Chapter close

References

Appendices
   1. Transcript extract notations
   2. References for Table 4
   3. University ethics approval
   4. Interview schedules for family members
5. Interview schedules for health care managers  
6. Examples of suggestive extracts from transcripts  
   Chapter 5: Extract from the interview with Peter  
7. Published journal abstracts relating to this thesis  
   Chapter 6
Abstract

Scope:

Few studies have investigated distinctive interpersonal characteristics of retained awareness and social engagement observed when individuals at different stages of dementia interact with their family members. Influencing this relational engagement are the subjective interpretations of family caregivers as they experience: (1) the fluctuating psychosocial landscape of dementia pre and post aged-care; (2) perceived psychological consequences of supporting a family member with dementia; (3) the transition to, and navigation of a hierarchical health care system. Additionally, few studies explore the subjective interpretations of health care managers working in dementia including: (1) their perception of their work role; (2) how they interpret the impact of such work on their own psychological wellbeing; and, (3) how they position themselves as witnesses within a health care system that impacts, often authoritatively, on family relationships.

Therefore, this thesis is concerned with the relational, psychosocial, and systemic domains of experiencing dementia. The triad of subjective expertise in experiencing dementia, and the relational and social engagement that occurs within this triad, underpins this research document. It seeks to advance our understanding of relational and social engagement throughout the stages of dementia, and inform models of care for optimising that engagement.

Objectives:

All who experience dementia, either through a diagnosis of dementia, or as a supporting family member or professional caregiver, are vulnerable to psychological distress from chronic and cumulative challenges to their psychological wellbeing. Therefore, this phenomenological interpretative thesis sought the subjective
experiences of dementia from a multi-faceted perspective. It sought observational studies of family communicative-interactions seeking to advance our understanding of family adaptation for interpersonal awareness and engagement throughout the stages of dementia, complemented by the subjective lived experience of supporting family members and health care managers. This research sought both positive and negative interpretations of experiences of dementia and aged care.

**Methodology:**

Overall, fifty-two participants were involved in this thesis. Video-recordings of family visits, and individual, dyad, and focus group semi-structured interviews provided the thesis data set. Two methodologies were employed, Interpretative Phenomenological Analysis (IPA; Smith, 1996) and Thematic Analysis (Braun & Clarke, 2006).

IPA sought reiterative subjective interpretations of the dementia experience from family and professional caregivers. It informed the semi-structured interviews, transcription, and analysis of collected interview data. IPA is an idiographic, hermeneutic, qualitative approach based on phenomenology and interpretative psychology. It aims to capture the idiosyncratic nature of each participant’s narrative and his or her interpreted experiences of rarely researched phenomenon (Smith, 1996). Symbolic interactionism explains the interaction between the researcher and the participant, as it posits that meaning can only be fully understood through the dynamic process of interpretation (Smith, 1996). A double hermeneutic allows both researcher and researched to engage in a reiterative meaning making process of understanding the lived experience.

Thematic Analysis conducted on the video-recorded data collected during family visits sought to break down relational and social engagement patterns that included the
individual with dementia, into interpreted themes by utilising non-obtrusive observation of families engaged in communication. Thematic Analysis goes beyond observable data to describe the phenomenon under investigation and explore latent patterns of meaning. This makes Thematic Analysis suitable for investigations of complex social phenomenology (Fereday & Muir-Cochrane, 2006; Joffe, 2012). From a critical realist perspective, Thematic Analysis maintains a focus on the individual yet also investigates the sociocultural context as it influences individual interactions (Braun & Clarke, 2006; Willig, 2013).

Collectively, superordinate and subordinate themes emerged from all data sets following robust discussion between independent auditors. These provide the results in each relevant chapter.

**Results:**

Fifty-two participants across seven studies connect the supporting, close-up, and contextual perspectives on relational and social engagement across a *triad of relational and social dementia expertise*. As the overarching phenomenological enquiry of this thesis, it linked the individuals with dementia to their family members and the health care managers who support them. A continuum of positive and negative insider perspectives of relational, psychosocial, and systemic aspects of dementia revealed varying patterns of engagement. They also highlighted the psychosocial struggle, the impact of dementia on psychological wellbeing, and the opportunity for psychological growth in these participants.

The construct *Relational Social Engagement (RSE)* developed from the studies in this thesis represents a complex and accessible set of relational interactions between the person with dementia and their family members, situated in distinctive familial bonds. It is manifest through family interactions, whereby individuals with dementia display
optimal engagement within family groups and can be positive (in-step) or negative (out-of-step). Family caregivers experience in-step interactions as connected, familiar, meaningful, and trusting whereby spontaneous adjustment to developments, opportunities for spontaneous fun, and feeling included and socially supported can occur. Alternatively, out-of-step interactions describe feelings of frustration and opposition. When out-of-step, shame, blame, guilt, and hypervigilance spill over to interactions in which individuals seek to control, conceal, reject, and escape. As such, RSE highlights distinctive familial bonds that offer security and comfort for those with dementia to spontaneously enjoy common ground and express differences within the family group. Although RSE can be positive in-step or negative out-of-step, it occurs more often within family groups during in-step interactions.

Conclusions:

This thesis can inform future research, theory, and aged care practice concerning relational and social engagement throughout the stages of dementia. Additionally, it highlights the complex interweave of psychosocial and relational distress experienced by these families as they navigate a western medicalised system of care. However, it also offers insight into the novice and convoluted engagement with a hierarchical model of care and its health care managers that presented the opportunity for the co-existence of traumatic distress and psychological growth.

Central to the outcomes of this thesis and the evidenced negative and positive family communication patterns within the observed interactions, complex levels of awareness were seen to occur in the family members with dementia in this study. Interpreted as RSE, and developed throughout the thesis and publications, RSE offers a construct for future research hypotheses that offer opportunities to preserve and optimise retained awareness and interpersonal skills in those living with dementia.
For the supporting family members, refusal of shame, rejection of stigma, and meaning brought to relational loss appeared to facilitate hope, and eventual positive redefinitions of relational and social intimacy as the stages of dementia progressed. Although theories of growth posit social support as a necessary condition for growth following adversity, when social support was lacking or even antagonistic for family caregivers, findings of this thesis would suggest that seeking RSE with a family member who has dementia stimulates meaning making for psychological growth. Generating renewed moral integrity and authenticity in family caregivers, RSE appeared to motivate their advocacy and positive change across other domains in time.

As a qualitative thesis, though these findings cannot be generalised to wider populations, the experience of these participants has provided hypothetical considerations for the researcher to critique. These include positive psychology approaches for living well with dementia and its impacts, and the emergence of qualitative philosophies to inform dementia practice and research. Implications for clinical psychologists seeking to facilitate RSE psychological growth in families are discussed at every level of investigation and summarised in Chapter 9.
## List of Tables

<table>
<thead>
<tr>
<th>Table 1:</th>
<th>Chapter map of this thesis</th>
<th>36</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 2:</td>
<td>Common causes of dementia</td>
<td>43</td>
</tr>
<tr>
<td>Table 3:</td>
<td>Symptomatic criteria of dementia</td>
<td>44</td>
</tr>
<tr>
<td>Table 4:</td>
<td>Dementia risk and prevention</td>
<td>48</td>
</tr>
<tr>
<td>Table 5:</td>
<td>Person-centred social interaction guidelines</td>
<td>58</td>
</tr>
<tr>
<td>Table 6:</td>
<td>Constructs and theories underpinning this thesis</td>
<td>96</td>
</tr>
<tr>
<td>Table 7:</td>
<td>Participating family groups</td>
<td>113</td>
</tr>
<tr>
<td>Table 8:</td>
<td>Participating health care managers</td>
<td>113</td>
</tr>
<tr>
<td>Table 9:</td>
<td>IPA for interviews</td>
<td>118</td>
</tr>
<tr>
<td>Table 10:</td>
<td>Thematic Analysis for video-recorded observations</td>
<td>121</td>
</tr>
<tr>
<td>Table 11:</td>
<td>Pilot-study participants</td>
<td>129</td>
</tr>
<tr>
<td>Table 12:</td>
<td>Pilot-study themes</td>
<td>130</td>
</tr>
<tr>
<td>Table 13:</td>
<td>Participants within the Chapter 5 studies</td>
<td>145</td>
</tr>
<tr>
<td>Table 14:</td>
<td>Themes: Systemic impacts on managers</td>
<td>146</td>
</tr>
<tr>
<td>Table 15:</td>
<td>Themes: Familial impacts witnessed by managers</td>
<td>157</td>
</tr>
<tr>
<td>Table 16:</td>
<td>Clinical Dementia Rating Scale: Moderate/Severe</td>
<td>181</td>
</tr>
<tr>
<td>Table 17:</td>
<td>Participants within the Chapter 6 studies</td>
<td>182</td>
</tr>
<tr>
<td>Table 18:</td>
<td>Themes: Family interactions in moderate dementia</td>
<td>184</td>
</tr>
<tr>
<td>Table 19:</td>
<td>Themes: Family interactions in severe dementia</td>
<td>198</td>
</tr>
<tr>
<td>Table 20:</td>
<td>Participants within the Chapter 7 studies</td>
<td>220</td>
</tr>
<tr>
<td>Table 21:</td>
<td>Themes: Systemic impacts on families</td>
<td>222</td>
</tr>
<tr>
<td>Table 22:</td>
<td>Themes: Relational impacts on families</td>
<td>233</td>
</tr>
</tbody>
</table>
List of Figures

**Figure 1:** Triad of relational and social dementia expertise 28

**Figure 2:** *Relational Social Engagement (RSE)* in context 269
# Glossary of Terms and Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AD</td>
<td>Alzheimer's disease</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
</tr>
<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
</tr>
<tr>
<td>APOE</td>
<td>Apolipoprotein E</td>
</tr>
<tr>
<td>BDNF</td>
<td>Brain-derived neurotrophic factor</td>
</tr>
<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>BPSD</td>
<td>Behavioural and psychological symptoms of dementia</td>
</tr>
<tr>
<td>CDR</td>
<td>Clinical Dementia Rating scale</td>
</tr>
<tr>
<td>CVD</td>
<td>Cardio-vascular dementia</td>
</tr>
<tr>
<td>DLB</td>
<td>Dementia with Lewy bodies</td>
</tr>
<tr>
<td>FTLD</td>
<td>Frontotemporal lobar degeneration</td>
</tr>
<tr>
<td>IPA</td>
<td>Interpretive Phenomenological Analysis</td>
</tr>
<tr>
<td>NSW</td>
<td>New South Wales</td>
</tr>
<tr>
<td>PMD</td>
<td>Person with moderate dementia</td>
</tr>
<tr>
<td>PSD</td>
<td>Person with severe dementia</td>
</tr>
<tr>
<td>RSE</td>
<td>Relational Social Engagement</td>
</tr>
<tr>
<td>TBI</td>
<td>Traumatic brain injury</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>