

**An interpretative phenomenological investigation
of dementia
from the perspective of families and system caregivers:

Stigma, traumatic loss, psychological growth, and
Relational Social Engagement (RSE).**

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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.

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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.

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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.

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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 4** Walmsley, B. D., & McCormack, L. (2016a). Synthesis of meaning: Negative and positive change in family members following the adversity of dementia. *Journal of Humanistic Psychology*, 56(2), 122–143.
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- Chapter 5** Walmsley, B. D., & McCormack, L. (2015a). Stigma, the medical model, and dementia care: Psychological growth in senior carers through moral and professional integrity. *Dementia*, 1–18. Online 12th March 2015:
<http://dx.doi.org/10.1177/1471301215574112>
- Walmsley, B. D., & McCormack, L. (2015b). Shame, hope, intimacy, and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*, 1–19. Online 27th February 2015:
<http://dx.doi.org/10.1177/1471301215573676>
- Chapter 6** Walmsley, B. D., & McCormack, L. (2016b). Severe dementia: Seeking *Relational Social Engagement* during family visits. *Aging & Mental Health*, 1–10. Online 5th September 2016: <http://dx.doi.org/10.1080/13607863.2016.1220923>;
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- 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:
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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.

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Glossary of Terms and Abbreviations

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