

Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology



Doctoral Thesis

April 2017

Emotional and systemic experiences of having a partner with dementia

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Doctorate in Clinical Psychology

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Word Count

Thesis Section	Text	Appendices (including references)	Total
Abstract	295	N/A	295
Literature Review	7,893	3,505	11,398
Research Paper	8,000	1,627	9,627
Critical Appraisal	2,958	200	3,158
Ethics Section	N/A	19,279	19,279
Appendices	N/A	5,339	5,339
Totals	19,146	28,950	49,096

Abstract

It is predicted that the number of people living with dementia worldwide will increase to 135.5 million by 2050 (World Health Organization, 2016). Moreover, the majority of people living with dementia are cared for within a community setting, primarily by their partner or family members. As a result of providing care individuals can experience a deterioration in their subjective psychological wellbeing, physical health and relationships. Consequently, the overall aim of this thesis was to explore the emotional and systemic experiences of having a partner with dementia. Specifically, a meta-synthesis was conducted to review the current understanding of the experiences of individuals whose partner is in long term care. The review synthesised the finding of thirteen qualitative studies using a meta-ethnographic approach (Noblit & Hare, 1988). As a result, four themes were identified which included; i) a continuation of social isolation; ii) challenges to planning for the future; iii) embracing the changing boundaries of marriage and iv) negotiating a new sense of self. Consequently the review highlighted the process of identity and role transition which individuals experience when their partner is living in long term care.

Furthermore, a study was conducted to explore the experience of self-conscious emotions (e.g. shame, guilt and pride) in individuals living with their partners who have dementia. Specifically, semi-structured interviews were conducted with eight partners living in the community. Moreover, the interviews were transcribed and the data analysed using an interpretative phenomenological approach. As a result, three themes emerged; 'guilt as a consequence of marriage beliefs and motivator of caring behaviour', 'discussing dementia elevates embarrassment but decreases guilt' and 'difficulty of feeling proud of caring within the traditional boundaries of marriage'. Consequently, the study acknowledged the impact of social expectations on individual's experience of self-conscious emotions and subsequently their behaviour.

Declaration

This thesis records work undertaken for the Doctorate in Clinical Psychology at Lancaster University's Division of Health Research from August 2015 to February 2017.

The work presented here is the author's own except where due reference is made. The work has not been submitted for the award of a higher degree elsewhere.

Name: Rachel Watterson

Signature:

Date:

Acknowledgements

I would like to thank all of the participants who so willingly gave their time and shared some of their most personal experiences for this research. Their honesty and courage to speak out has given a voice to those who are unable to have their voices heard. Also, without my supervisors Jane and Liliana this research would not have happened; you both supported me to reach my potential and for that I am forever grateful.

I also could not have achieved everything I have without the unconditional love and support from my mum and dad. You always believed I could be whatever I wanted to be and that belief has truly kept me going when things got tough. And finally, I want to thank my wonderful husband and team-mate, Sean. I could never thank you enough for your endless compassion, patience and love throughout these challenging few years. Without you all I would not be here saying, I finally made it!

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