

Exploring informal caregivers' health needs from a capability perspective.

A thesis presented in partial fulfilment of the requirements for the degree of

Doctor of Philosophy

in

Psychology

at Massey University, Manawatū, New Zealand.

Barbara Mary Horrell

2015

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

Abstract

Despite more than forty years of informal caregiving research, the health needs of informal caregivers continue to generate considerable scrutiny. Most commonly, caregiving is portrayed as burdensome and a health risk, although positive and ambivalent experiences have been reported. This study uses the Capability Approach (CA; e.g. Nussbaum, 2000; Sen, 1980) as a theoretical framework to add another perspective to the existing literature regarding informal care provision for older people. Participatory principles informed the research, insofar as the participants were accorded flexibility, control, and helped to co-analyse some of the data. Undertaken in New Zealand, the research comprised two studies. In Study One, 60 caregivers anonymously participated in an online research forum, in an evolving joint discussion of their health needs. Template analysis (King, 2012) of the forum postings, based on Nussbaum's (2007) capabilities list, highlighted the relational nature of caregiving and the importance of emotions to the caregiving role. Emotional attachment influenced the caregivers' freedom to choose how they lived their lives, and emotions in general were implicated in the complexities and tensions associated with the caregiving process. An important finding was the self-abnegation of the caregivers who neglected self-care in order to provide care for another. These results led to a second, prospective study that explored in more depth the role of emotions in the everyday lives of caregivers. Six informal caregivers participated in Study Two which involved up to six successive interviews with each participant. Four of the participants kept a solicited diary, which informed the subsequent interviews. Narratives from the second study provided more nuanced data that affirmed the first study's findings, and contributed to the overall finding that an ethic of care underpins the provision of informal care for older people. The participants valued having the capability to care, evidenced by their emotional attachment, attentiveness and commitment to providing competent care. The participants approach to self-care and their own wellbeing was inseparable from the wellbeing of the person being cared-for. These findings have important implications for social policy aimed at improving the experience of providing informal care for older people.

Preface

The social location for this thesis is New Zealand. The data were collected between 2010 and 2013. The thesis is organised around six research manuscripts. The first manuscript has been published in a Special Issue of *Qualitative Research in Psychology*:

Horrell, B., Stephens, C., & Breheny, M. (2015). Online research with informal caregivers: Opportunities and challenges. *Qualitative Research in Psychology*, 12(3), 258-271.

The second manuscript has been submitted to *The Scandinavian Journal of Caring Sciences* and the third paper was published in a Special Issue in *Health Psychology*:

Horrell, B., Stephens, C., & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers for older people. *Health Psychology*, 34(4), 339.

Manuscripts four and five will be submitted in the future.

The sixth manuscript was published in 2014 in *Vulnerable Groups & Inclusion*:

<http://dx.doi.org/10.3402/vgi.v5.24357>

The manuscripts are presented as published, or submitted, and therefore there is some inconsistency throughout the thesis with regard to referencing styles and language, e.g. a shift between UK and US spelling, due to the different journal requirements.

The ideas presented in this thesis are my own. My supervisors, Christine Stephens and Mary Breheny have provided support through helping me to structure my arguments, strengthen my analytical skills and hone the manuscripts submitted for publication.

For this reason they are included as co-authors on all six papers.

Acknowledgements

Firstly, I give my sincere thanks to the participants, and the people they care for. Without you this study would not have happened. Your generosity, warmth, insight and humour were what I enjoyed most in constructing this thesis. I have been humbled and inspired by the lives that you lead and the stories that you have told. I hope that I have done justice to the information that you have shared and I hope that our collaboration will help to improve the future health and wellbeing of informal caregivers for older people.

Next, I wish to thank my supervisors, Christine Stephens and Mary Breheny. It has been a long journey, and I would not have reached the end without your kindness, patience and humour. I hope you never experience another student who tries to read every piece ever written about tangential topics, or falters so often along the way! You have been unfailingly available to dispense your wisdom. Your depth of knowledge and clarity has been an inspiration; I have learned much under your guidance, academically and personally, for which I am very grateful.

To my family – it is done! Thank you for your love and support in the self-imposed frantic dash to the finish line, and special thanks to Kate.

Finally, I would like to acknowledge the funding received from the New Zealand Foundation for Research Science and Technology, now Ministry of Business, Innovation, and Employment, whose generous assistance made this study possible.

Contents

| | |
|--|-----|
| Exploring informal caregivers' health needs from a capability perspective..... | i |
| Abstract..... | i |
| Preface | iii |
| Acknowledgements..... | v |
| Contents | vii |
| Chapter One: Introduction | 1 |
| References | 4 |
| Chapter Two: Informal Caregiving - Background..... | 5 |
| Introduction | 5 |
| An historical overview | 5 |
| The nature of care | 6 |
| Feminist scholarship | 9 |
| An ethic of care | 9 |
| Terminology | 10 |
| Caregiving for older people: a topical issue..... | 12 |
| The prevalence of informal caregiving for older people | 15 |
| What informal caregivers do | 16 |
| Chapter summary | 17 |
| References | 18 |
| Chapter Three: The effects of informal caregiving..... | 25 |
| Introduction | 25 |
| Burden | 25 |
| Benefit..... | 31 |
| Ambivalence | 32 |
| Equivocality..... | 35 |
| Support for caregivers | 36 |
| Conclusion..... | 38 |
| References | 39 |
| Link Between Chapters Three and Four | 51 |
| Chapter Four: The Capability Approach | 53 |
| Introduction | 53 |
| Conceptualising health | 53 |
| Background to the Capability Approach (CA) | 55 |
| Choosing capabilities | 57 |

| | |
|---|-----|
| What the CA can add to informal care research | 66 |
| The thesis aim | 67 |
| References | 68 |
| About the Author | 73 |
| Link between Chapter Four and Chapter Five | 77 |
| Reference | 78 |
| Chapter Five: Study One - Method | 79 |
| Abstract | 79 |
| Online research with informal caregivers: opportunities and challenges. | 80 |
| Introduction | 80 |
| An Asynchronous Online Forum. | 81 |
| Creating the website | 82 |
| Recruitment | 84 |
| Participants | 85 |
| Ethical considerations | 86 |
| Conclusion | 94 |
| References | 96 |
| Link between Chapter Five and Chapter Six | 103 |
| Nussbaum's (2007) List of Capabilities | 105 |
| References | 107 |
| Chapter Six: Study One - 1st results paper | 109 |
| Abstract | 109 |
| Informal caregiving for older people: using Nussbaum's central capabilities to understand care | 110 |
| Introduction | 110 |
| Informal Care | 111 |
| Method | 112 |
| Recruitment | 113 |
| Participants | 113 |
| Procedure | 114 |
| Analysis | 114 |
| Results and Discussion | 115 |
| Nussbaum's List | 115 |
| Life | 115 |
| Bodily Health | 116 |
| Bodily Integrity | 119 |

| | |
|--|-----|
| Senses, Imagination and Thought..... | 119 |
| Emotions | 120 |
| Practical reason..... | 123 |
| Affiliation | 125 |
| Other Species | 127 |
| Play..... | 128 |
| Control over One’s Environment | 129 |
| Conclusion..... | 130 |
| References | 133 |
| Link between Chapter Six and Chapter Seven | 141 |
| References | 143 |
| Chapter Seven: Study One - 2nd results paper | 145 |
| Abstract..... | 145 |
| Capability to Care: Supporting the Health of Informal Caregivers for Older People..... | 146 |
| Introduction | 146 |
| The Capability Approach..... | 149 |
| Method | 151 |
| Participants and procedure | 151 |
| Analysis | 154 |
| Presentation of results..... | 155 |
| Results and Discussion..... | 156 |
| Capabilities in the Context of Caregiving..... | 156 |
| Capability, caregiving and emotions..... | 158 |
| The capability to care..... | 158 |
| Conflicting emotions | 160 |
| Trade-offs..... | 165 |
| One day my life will go on..... | 167 |
| Conclusion..... | 169 |
| References | 172 |
| Link between Chapter Seven and Chapter Eight | 181 |
| Chapter Eight: Study Two - Method..... | 185 |
| Abstract..... | 185 |
| Informal caregiving for older people : insights from using a diary/interview methodology ... | 186 |
| Introduction | 186 |
| Method | 180 |

| | |
|--|-----|
| “A time for me to reflect on my life as a carer” | 184 |
| Diary-Interview method..... | 194 |
| Limitations and Challenges | 199 |
| Conclusion..... | 200 |
| References | 201 |
| Link between Chapter Eight and Chapter Nine | 209 |
| Narrative analysis | 209 |
| References | 211 |
| Chapter Nine: Study Two - Results | 213 |
| Abstract..... | 213 |
| Informal caregiving for older people: a relational narrative of acceptance | 214 |
| Introduction | 214 |
| Method | 217 |
| Recruitment | 217 |
| Participants and Procedure | 217 |
| Analysis | 218 |
| Results and Discussion..... | 216 |
| Pollyanna’s story..... | 216 |
| Ciara’s story | 219 |
| Allan’s story..... | 221 |
| Emily’s story | 223 |
| Doug’s story | 225 |
| Ian’s story..... | 227 |
| Conclusion..... | 233 |
| References | 234 |
| Chapter Ten: Capability to care and work - when dual roles intersect | 239 |
| Abstract..... | 239 |
| Introduction | 240 |
| Method | 244 |
| STUDY ONE: CARERSVOICESNZ..... | 245 |
| Results and Discussion..... | 247 |
| Caring decisions | 247 |
| Employment and finances | 248 |
| Finding a balance | 249 |
| STUDY TWO: CIARA’S STORY | 252 |

| | |
|---|-----|
| Results and Discussion..... | 253 |
| The caring caregiver..... | 254 |
| The successful businesswoman | 257 |
| The juggler | 259 |
| The implications of juggling | 261 |
| Conclusion..... | 263 |
| References | 264 |
| Final Reflections from the author | 271 |
| References | 273 |
| Conclusion | 275 |
| Implications for future theoretical and empirical research..... | 279 |
| Implications for policy..... | 280 |
| Future research..... | 283 |
| Limitations | 284 |
| Conclusion..... | 286 |
| References | 287 |
| Appendices | 291 |
| Appendix A:..... | 291 |
| Nussbaum’s List of Central Human Capabilities | 291 |
| Appendix B..... | 294 |
| CARERS’ VOICES: | 294 |
| Appendix C..... | 298 |
| Letter to Support Organisations | 298 |
| Appendix D..... | 301 |
| carersvoicesnz - Summary of results | 301 |
| Appendix E | 303 |
| Caring for Elders in the Community: Focussing on Feelings..... | 303 |
| Appendix F | 307 |
| Caring for Elders in the Community: Focussing on Feelings..... | 307 |
| Appendix G..... | 309 |
| Screenshots of the carersvoicesnz Forum | 309 |

