

Exploring informal caregivers' health needs from a capability perspective.

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

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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.

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