



## Family caring of older adults with intellectual disability and coping according to loci of responsibility



Teresa Iacono<sup>a,\*</sup>, Elizabeth Evans<sup>b</sup>, Adrian Davis<sup>b</sup>, Anjali Bhardwaj<sup>b</sup>,  
Beth Turner<sup>b</sup>, Jennifer Torr<sup>c</sup>, Julian N. Trollor<sup>b,d</sup>

<sup>a</sup> La Trobe Rural Health School, La Trobe University, P.O. Box 199, Bendigo, VIC, Australia

<sup>b</sup> Department of Developmental Disability Neuropsychiatry, University of New South Wales, Sydney, Australia

<sup>c</sup> Centre for Developmental Disability Health Victoria, Monash University, Melbourne, Australia

<sup>d</sup> Centre for Healthy Brain Ageing, University of New South Wales, Sydney, Australia

### ARTICLE INFO

#### Article history:

Received 4 February 2016

Received in revised form 23 May 2016

Accepted 6 July 2016

Available online 18 July 2016

Number of reviews completed is 2

#### Keywords:

Australia

Family caregiver

Ageing

Intellectual disability

Coping

### ABSTRACT

**Background:** A complex interplay of factors is evident in the response of family caring for older adults with intellectual disability (ID). The aim of this study was to explore the interaction of these factors.

**Methods:** Quantitative data on health and wellbeing, and coping strategies were obtained for carers and their adult children with ID. Qualitative data were from three focus groups conducted with 19 main family carers.

**Results:** Carers varied in their health and wellbeing. Four overarching themes emerged from an initial interpretative phenomenological analysis of the qualitative data: loci of responsibility, impacts of caring and responses to it on health and wellbeing, transitioning care responsibilities, and interrelationships around the caring role. Further interrogation of data according to carers' coping strategies revealed three loci of responsibility, providing a point of convergence that related to carer experiences, plans for transition, and relationships within families. These loci of responsibility were having sole responsibility because there was no-one else, having sole responsibility because no-one could do it better, and sharing responsibility.

**Conclusion:** The loci of responsibility provide a means to understand carers' appraisal of their role and the degree of control they have over it, and may account for varied coping strategies adopted.

© 2016 Elsevier Ltd. All rights reserved.

### What this study adds

This study addressed a need to understand family carer response to long term caring of adults with intellectual disabilities (ID) as they age. Using a mixed methods approach, we sought to understand the varied experiences of caring and role appraisal amongst family carers of older adults with ID. Quantitative data provided a general understanding of reported levels of distress, depression, subjective burden, and social supports for 13 carers. They showed a varied picture across these areas, reflecting previous findings. Qualitative data from 3 focus groups involving these 13 and an additional 6 family carers similarly reflected previous findings relating to their role appraisal, how caring impacted on their health and wellbeing,

\* Corresponding author.

E-mail address: [t.iacono@latrobe.edu.au](mailto:t.iacono@latrobe.edu.au) (T. Iacono).

concerns about care transitions, and interrelationships. In applying a second level of analysis, whereby we sought examples of coping strategies identified using our quantitative tool, we were able to develop a deeper understanding of these experiences than has been evident in previous studies by exploring how the Loci of Responsibility for caring influenced their response. This appraisal of their responsibility provided a lens through which carer adoption of various types of coping strategies, wellbeing, future planning, and interrelationships around the caring role could be explained.

## 1. Introduction

An outcome of the increased life expectancy of people with intellectual disabilities (ID) has been extending the caring career for parents (Grant & Ramcharan, 2001; Todd & Shearn, 1996). Further, siblings increasingly adopt the carer role, which may include both the family member with disability and parents (Greenberg, Seltzer, & Greenley, 1993). The wellbeing of family carers appears to be influenced by their objective and subjective experience of demands, and their responses in terms of stress and coping (Grant & Whittell, 2000).

Demands on carers have been found to vary according to the severity of the relative's intellectual disability (Chou, Fu, Lin, & Lee, 2011) and presence of co-existing conditions, such as mental health problems or challenging behaviour (Maes, Broekman, Došen, & Nauts, 2003), and whether the person with disability and the carer cohabitate (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). These care demands can lead to high levels of stress and family burden (Eley, Boyes, Young, & Hegney, 2009; Grant & Ramcharan, 2001). For carers of adult children with ID, age-related health conditions for both carers and care recipient (Llewellyn, McConnell, Gething, Cant, & Kendig, 2010; Seltzer et al., 2001) and concerns about who will take on the carer role when parents are no longer able (Bigby, Bowers, & Webber, 2011; Eley et al., 2009) can further contribute to stress, with consequences for carer wellbeing, including mental health. Depression, in particular, has been associated with the same variables that predict stress, such as carer age (Llewellyn et al., 2010; Seltzer et al., 2001), co-residency with the care recipient (Seltzer et al., 2001), and the amount of time spent caring (Llewellyn et al., 2010).

In contrast to reports of negative experiences and outcomes of caring, Breitenbach (2004) highlighted positive aspects enabling the role to be sustained over time. Compared to their younger peers, older parents of people with ID have reported more gratification in their caring role as they age, allowing them to maintain intimacy, assertiveness and a sense of control (Tobin, 1996). The nature of the experience therefore, may relate to carer appraisal of their role. Carers who have a sense of control, for example, may be less susceptible to potential negative effects of high care demands (Essex, Seltzer, & Krauss, 1999; Llewellyn et al., 2010; Todd & Shearn, 1996). On the other hand, these families may experience stress when they perceive a loss of control, such as may occur when a crisis, such as illness or death, results in a sudden transition (Bibby, 2013; Eley et al., 2009; Grey, Griffith, Totsika, & Hastings, 2015).

As parents age, the potential for siblings, rather than services, to take on caring responsibility increases (Bigby et al., 2011). Sibling carers have reported stress in relationships with family members, poor quality of life, and concerns about future plans, government funding, and physical and emotional support (Eley et al., 2009; Greenberg, Seltzer, Orsmond, & Krauss, 1999). In contrast to parental carers, little research attention has been paid to potential mediators of burden or stress experienced by siblings in these long term caring roles.

The picture that emerges is of factors influencing the relationship between the subjective experience of carer burden and stress responses. Carer coping style has been implicated as a potential mediator between carer burden and feelings of stress that may result in poor carer physical and mental health (Kim & Chung, 2015; Llewellyn et al., 2010). Llewellyn et al. (2010), for example, found "well-honed coping strategies" (p. 1184) amongst 64 parent carers aged from 52 to 90 years, which went some way towards mitigating against feelings of overwhelming burden. Kim and Chung (2015) found that adopting a problem-focused coping strategy that resulted in activities such as permanency planning, reduced worry and increased carer satisfaction amongst older mothers caring for their adult children with ID.

It is evident then that understanding the role in and experience of caring for adult children with ID as parents themselves age, as well as that of siblings who may share the care and/or support their parents, requires exploration. Of particular interest are coping styles, given their potential to influence stress responses.

Cognitive appraisals of situations, and then of coping resources (Grant & Ramcharan, 2001) arguably explain the different stress responses found across carers. Various coping styles that relate to how a person appraises stressful situations and then responds to them have been proposed and tested empirically (Llewellyn et al., 2010). Based on the work of Lazarus and Folkman (1984), two broad types of coping processes have been described: (a) problem-focused, resulting in attempts to employ cognitive or behavioural solutions; and (b) emotion-focused, resulting in attempts to reduce or manage emotional distress (Essex et al., 1999). Also identified from the work of Carver and colleagues (Carver, Scheier, & Kumari Weintraub, 1989) were strategies categorised as dysfunctional, involving behavioural and mental disengagement, venting and reliance on substances (Carver et al., 1989; Coolidge, Segal, Hook, & Stewart, 2000). Problem-focused and emotion-focused (including those described as dysfunctional) coping styles have been found to be used, to varying degrees, by carers of children (Hastings et al., 2005) and adults with disability (Essex et al., 1999). Further, differences have been found across gender, with mothers using more problem-focussed strategies than fathers (Essex et al., 1999), and age groups, with older carers argued to have developed an expanded array of coping strategies not seen in younger carers (Grant & Whittell, 2000).

The complex interplay of factors related to the wellbeing of family carers of older adults with ID was explored in a larger study, of which this study forms a part. The Successful Ageing in ID (SAge-ID) is a longitudinal study of adults with ID, aged 40 years and older, and their family carers. Using cross-sectional questionnaire data, Evans, Trollor, Davis, Bhardwaj,

Download English Version:

<https://daneshyari.com/en/article/371014>

Download Persian Version:

<https://daneshyari.com/article/371014>

[Daneshyari.com](https://daneshyari.com)