



Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample

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ABSTRACT

Background: Older parent-carers in Australia are the subject of increasing policy and practice attention due to concerns about their ongoing ability to care in the light of their own ageing and the ageing of their adult son or daughter. This paper examines health status and the coping strategies of a group of older Australian parents caring for an adult son or daughter with intellectual disabilities.

Method: Health status using the SF-12 (Ware, Snow, Kosinski, & Gandek, 1993), caring stress using the CADI (Nolan, Grant, & Keady, 1998), and coping strategies using the CAMI (Nolan et al., 1998) were assessed in 64 older parent-carers of adults with intellectual disabilities.

Results: The self-reported health status of this sample of older parent-carers did not differ significantly from Australian population norms, with one exception. That is, the younger parent-carers in the sample (55–64 years) reported significantly poorer mental health. Better health was associated with having a partner, a larger and close support network of family, friends and neighbours, and a lower care-load. Overall, the study participants identified both satisfaction as well as stress associated with caring, a finding that runs counter to the common perception that being a carer is overwhelmingly burdensome. Common sources of stress were feeling helpless or not in control, and poor professional support. Analysis of older parent-carers coping strategies suggests that self-reliance, whether by choice or necessity, was the norm.

Conclusions: The health status of older parent-carers may present less cause for concern than anecdotal reports suggest. That said, the strong self-reliance particularly of the older carers presents a challenge to service providers seeking to engage those whose situation appears to warrant support from the service system.

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1. Introduction

An increasing number of Australian parents are caring well into later life for their adult son or daughter with intellectual disabilities (Australian Institute of Health and Welfare [AIHW], 2000). This trend is associated with the ageing of the baby boom generation which includes a population bulge of people with disabilities and, with increased life expectancy, many more children with disabilities living into adulthood (Seltzer, Greenberg, Krauss, & Hong, 1997). Older parent-carers are thought to be potentially vulnerable in later life as they experience their own ageing at the same time as continuing their parenting and caring responsibilities (Schofield et al., 1999; Seltzer & Krauss, 1994). As a consequence, Federal and state government policies specifically identify this group of parent-carers for targeted programs and interventions.

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There are close to one half million primary carers in Australia, including persons caring for a parent, spouse, sibling, son or daughter with disabilities (AIHW, 2004). The social and economic significance of this family care effort cannot be understated. The unpaid labour of Australian primary carers has been valued at more than \$19 billion per annum, dwarfing the total government contribution to welfare services (AIHW, 2004). However, there may be a personal health cost in contributing to this family care effort. Research findings suggest that primary carers experience higher age-specific rates of disability and are at-risk for debilitating stress, anxiety and depression (AIHW, 2004; Emerson, Robertson, & Wood, 2004; Hatton & Emerson, 2003; Schofield et al., 1999; White & Hastings, 2004). In this paper we report findings on the health status of a sample of older parent-carers in Australia, the stresses they experience, and their coping strategies gathered in the context of a narrative life history study investigating care pathways over a lifetime (Llewellyn, 2003; Llewellyn, Gething, Kendig, & Cant, 2004).

The health of older parent-carers may be particularly at-risk as the effects of ageing and the toil of forty or more years of caregiving take their toll. This accumulation of effects is referred to as the 'wear and tear' hypothesis, predicated on demands exponentially increasing in later life. For example, parent-carers may have to contend with the early 'forced' retirement of their son or daughter from supported employment or day programs and, with increasing age, their adult son or daughter may experience new health problems such as anxiety and depression (Davidson, Prasher & Janicki, 2003). In addition, older parent-carers have the future to consider: older parent-carers share a general anxiety about how their son or daughter will fare in their absence (Llewellyn, 2003; Twigg & Atkin, 1994).

The research data on the health of older parent-carers of adults with intellectual disabilities is scarce however and provides little support for the 'wear and tear' hypothesis. Indeed, Chen, Ryan-Henry, Heller, and Chen (2001) found that the self-reported physical and mental health status of 108 mid to later life mothers of adults with intellectual disabilities, measured using the MOS SF36, was similar to or better than US national norms. Similarly, Carr (2005) found no significant difference in health status between older parent-carers of adults with Down's syndrome and a matched control group. Seltzer and her colleagues (Seltzer & Krauss, 1989; Seltzer, Greenberg, & Krauss, 1995) have reported that older parent-carers of adults with intellectual disabilities are, on average, less stressed than younger carers (e.g., Seltzer & Krauss, 1989) and fare well compared to other older parent-carers who, in many instances, have endured shorter caregiving careers, such as those caring for sons and daughters with mental illness (e.g., Seltzer et al., 1995).

A number of factors may contribute to explaining this seemingly 'good health' of older parent-carers of adults with intellectual disabilities. One factor is sample selection bias. In other words, parent-carers who experience health problems are more likely to seek alternative care arrangements earlier in life and so not be caring full time in later life (Howe, Schofield, & Herrman, 1997). Another factor, which is drawing increased research attention, is parent-carer adaptation (Grant, Nolan, & Keady, 2003). Specifically, older parent-carers may enjoy better health-for-age because they have enhanced self-confidence, sense of control and a well-honed repertoire of coping strategies (i.e., 'the adaptation hypothesis') (Grant, 2005). Older parent-carers' experiences may well be enriched by increasing reciprocity with their adult son or daughter with intellectual disabilities taking on some caring activities for their elderly parents, and this may incur health benefits (Williams & Robinson, 2001).

There is no question that family caregivers face unique and complex challenges. There is a substantive literature that attests to the stress and strain associated with caring for an adult son or daughter with disabilities (e.g., Hayden & Heller, 1997; Pruchno & Patrick, 1999). This literature draws primarily on psychological models focusing almost exclusively on the tragedy, ongoing grief and related burden for parents faced with raising a child with a disability. However the assumption that burden and its accompanying stressors are a foregone conclusion of disability has been contested. As Helff and Glidden (1998) noted increasingly researchers are questioning the singular stress and burden perspective and reporting that reward and gratifications do occur with caring (see for example Grant & Whittell, 2000; Grant, Ramcharan, McGrath, Nolan, & Keady, 1998).

A number of variables have been shown to mediate or moderate the physical and psychological effects of caring for a family member with a disability. These include the characteristics of the adult receiving care, such as maladaptive behaviour, and the level of help they require with everyday personal care tasks (Hayden & Goldman, 1996; Heller, Miller, & Facto, 1997; Maes, Broekman, Dosen, & Nauts, 2003). Parent characteristics such as age and gender also appear to play a part (Essex, Seltzer, & Krauss, 1999; Grant & Whittell, 2000; Pruchno & Patrick, 1999). Finally, parental access to resources such as income, social support and formal services also appear to influence parents' health and wellbeing (Hong, Seltzer, & Krauss, 2001).

As well as identifying variation in the effects of caring on parental health and wellbeing, research is also beginning to uncover diversity in the coping strategies employed by parent-carers of children and adults with intellectual disabilities. Informed by a transactional model of stress and coping, a number of studies have focused on carers' appraisals of potentially stressful circumstances and the resources they muster to deal with these (e.g., Grant & Ramcharan, 2001; Grant & Whittell, 2000; Kim, Greenberg, Seltzer, & Krauss, 2003). For example, Grant and Whittell (2000) investigated the coping strategies of thirty parent-carers of children and adults with intellectual disabilities. The study used the Carers Assessment of Difficulties Index (CADI), and the Carers Assessment of Managing Index (CAMI) (Nolan, Grant, & Keady, 1998), to tap carers' appraisals of various stressors and coping strategies. The parent-carers were found to use a variety of coping strategies which were differentiated by gender, life stage and family composition. For example, the coping strategies of older parent-carers were reportedly different to those of younger parent-carers, specifically, they were more accepting of their situation, and were adept at reframing the meaning of their situation.

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