

The impact of caring on caregivers' mental health: a review of the literature

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Abstract

This paper provides a brief overview of the literature on the impact of caring on the mental health of informal caregivers in the areas of aged care, disability and mental health. Factors discussed that may impact on caregivers' mental health include the relationship between the caregiver and care recipient, the nature of the care recipient's disability and the stage of the caregiving process. Several moderators of the impact of caring on mental health are described, including socio-economic factors, social support and coping strategies. This information provides a context within which to examine the type of interventions appropriate to assist caregivers in various situations.

Introduction

Given recent Federal Government announcements on the importance of supporting informal caregivers in their caregiving role (Australian Department of Health and Ageing, 2002), it is timely to consider some of the issues related to this role. This is particularly so given the probability that as the percentage of older Australians increases, many more individuals will find themselves thrust into the role of unpaid caregiver. The impact of caregiving on the mental health of caregivers is well documented and warrants careful assessment when support structures for caregivers are considered and procedures implemented. Efforts to support caregivers in their role should ideally lessen the negative physical and mental effects that caring can have on their health. It is also known that the impact of caring on caregivers' mental health is different for individual caregivers. Some caregivers experience a substantial negative impact while others are less affected by the caring role. This variation in the impact experienced is not simply related to the extent of caregiving provided (Schofield, Bloch, Herrman, Murphy, Nankervis & Singh, 1998).

This paper presents a brief overview of the literature on the impact of caring on the mental health of caregivers. It encompasses caregivers of persons of all ages and covers aged care, mental health and disability. A caregiver is defined as a relative, friend or neighbour who provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living. The person who is receiving care is the care recipient, defined as a person who lives with some form of chronic condition that causes difficulties in completing the tasks of daily living. This review provides information that helps address the question of how best to support caregivers, and will inform the development and implementation of interventions to sustain caregivers in their role.

Method

This paper is derived from a larger overview of the literature on sustaining caregiving relationships (Savage, 2002). The published literature was sourced utilising the PsychINFO, CINAHL and Medline databases. Terms searched were 'carer' and 'caregiver' with 'impact', 'support', 'coping' and 'interventions'. Reports and conference proceedings were sourced via internet searches and contacts with workers in the field. More recent literature and Australian research is included where possible, and relevant reviews have been summarised where possible.

The impact of caregiving

The negative impact of caregiving on the mental health of caregivers is substantiated in the literature. For example, the Victorian Carers Program conducted a population-based study in which differences in well-being between caregivers, as a group, and non-caregivers were demonstrated (Schofield et al., 1998). The researchers found less life satisfaction, less positive affect, and more negative affect among caregivers compared with non-caregivers, regardless of age or marital status. In data collected by the Australian Bureau of Statistics (ABS), approximately 30% of caregivers reported that their well-being had been affected by caregiving, and that they were often worried or depressed (ABS, 1998). In a review of 41 studies published between 1990 and 1995 on the effects on caregivers of care recipients with dementia, it was reported that increased levels of psychiatric morbidity were generally found, with elevated levels of depression being a consistent finding (Schultz, O'Brien, Bookwala & Fleissner, 1995).

Some researchers have investigated the positive aspects of caring, such as the satisfaction experienced by caregivers in performing their caring role. Important positive aspects of the caregiving role include giving pleasure to the care recipient, maintaining the dignity and maximising the potential of the care recipient, experiencing enhanced relationships, meeting perceived responsibilities, sharing mutual love and support, and developing personally (Nolan, Grant & Keady, 1996; Lundh, 1999). In the Victorian Carers Program research, 84% of caregivers indicated that they receive a great deal of satisfaction from caring (Schofield et al., 1998). Caregivers in overseas research also described some benefits of caring, such as a sense of closeness to the care recipient, and enhanced self-esteem (Ashworth & Baker, 2000). In the ABS data, 33% of caregivers indicated that their relationship with the care recipient was closer as a result of their caregiving role (ABS, 1998). It is likely that these positive aspects of caring would impact positively on the caregiver's overall mental health.

Factors associated with the impact of caring

Some of the factors that affect the impact of caregiving on caregivers' mental health are related to the caregiving situation itself, such as the relationship with the care recipient and the type of disability of the care recipient. Clearly these factors are extremely important when assessing the most appropriate supports for individual caregivers or for caregiver groups.

Relationship between caregiver and care recipient

The relationship of the caregiver to the care recipient has been reported to be an influential factor in relation to the impact of caregiving. In the Victorian Carers Program research, spouse caregivers experienced lower positive affect than did parents and adult offspring (Schofield et al., 1998). Parents reported more satisfaction with the caring role than did spouses, and spouses reported more satisfaction than did adult offspring. Also, parents and spouses reported more closeness in their family than did adult offspring. In the review of research on dementia caregivers, being the patient's spouse was associated with increased depression (Schultz et al., 1995). Further, Nolan et al. (1996) noted differences in the perceived satisfaction of caregivers who were spouses of the care recipient compared with those who were children of the care recipient.

Living with the care recipient was associated with a greater negative effect on well-being, and less satisfaction, than not living with the care recipient in the ABS data (1998). Similarly, Baronet (1999) found that residing with a relative with a mental illness increased the experience of burden.

How close the relationship is between caregiver and care recipient appears to be important also. Parents and spouses tended to be more positively involved in caregiving than did adult offspring in the Victorian Carers Program research (Schofield et al., 1998). Intimacy and love in the relationship between caregiver and care recipient have been associated with lower levels of minor psychiatric symptoms and burden (Braithwaite, 2000), and the quality of the relationship between a caregiver and a care recipient who is their parent may have an influence on the ability to be satisfied with family functioning (Carruth, Tate, Moffatt, & Hill, 1997). It has also been suggested that depressive symptoms, anger and resentment may be experienced by caregivers in very close or enmeshed families if they have taken on the caregiving role to conform to family rules (Carruth et al., 1997).

Care recipient's disability

Some aspects of the impact of caregiving on the caregiver's mental health differ depending on the nature of the care recipient's disability. For example, caring for a person with mental illness may involve a degree of uncertainty for the caregiver, a lack of control for the caregiver and manipulation by the care recipient. For caregivers whose care recipient has dementia, there is the loss of the person who once was, and witnessing the gradual decline of that person. Caregivers who are parents of children with disabilities may need to deal with the knowledge that their child will not develop as other children do, and the milestones celebrated by other parents may be times of grief for them. As caregivers who are parents of adults with disabilities age themselves, they face the additional concern of who will care for their child when they are no longer able to (Bigby & Ozanne, 1999).

Schofield et al. (1998) concluded that caregivers of people with a physical impairment who are intellectually intact express a greater sense of well-being than do caregivers of people who are affected intellectually. In a study by Hoare, Harris, Jackson and Kerley (1998), greater distress in caregivers of severely intellectually disabled children was associated with increased disability in the child. Similarly, the presence of behavioural problems in the care recipient with dementia was associated with increased depression in the caregiver (Schultz et al., 1995). However, a comparison of mothers of adults with mental health problems with mothers of adults with intellectual disability found that the latter group experienced greater gratification and a better relationship with the care recipient than did mothers of an adult with mental health problems (Greenberg, Seltzer & Greenley, 1993). In the latter study, mothers of adults with mental health problems reported more behaviour problems in their care recipient (Greenberg et al., 1993).

The stage in the caregiving process

There is also evidence that where caregivers are at in their caring career influences the impact of caring on their mental health (Avison, Turner, Noh & Speechley, 1993). In the case of caregivers of persons with dementia, for example, Nolan et al. (1996) described various stages that the caregiver may go through in response to the caring situation. These include noticing, discounting / normalising, suspecting, searching for explanations, recounting, taking it on, going through it, and turning it over (Nolan et al., 1996). Different effects of caring on caregivers' mental health would be expected at each stage in the caregiving process. How long caregivers have been in the caregiving role, and their stage, needs to be taken into account when providing services to caregivers (Nolan et al., 1996).

Moderators of the impact of caregiving

The mental health impact of the challenges faced by caregivers may be mediated or moderated by a number of factors, and these factors need to be considered when planning how to support individual caregivers. Moderating factors include the financial situation of caregivers, the amount of social support caregivers have,

the coping strategies they employ, and their own sense of mastery or self-esteem. Many of these factors can be described as coping responses, and categorised as coping resources or coping strategies (Nolan et al., 1996). Coping resources are the kinds of resources people are able to call upon in managing situations, and include one's financial position and the social support available to one. Coping strategies are how people cope (Nolan et al., 1996).

The important role played by mediating factors is affirmed in the literature. Pearlin, Mullan, Semple and Skaff (1990) suggested that while the mediating factors of coping and social support cannot explain all of the difference between the stress experienced by different caregivers in similar situations, they can have a major explanatory role. A recent study involving parents of autistic children concluded that stressors were not a direct predictor of negative outcomes, but that their influence was moderated by social support and coping style (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001).

Socioeconomic factors

The literature indicates that financial instability, as well as being caused to some extent by the caregiving role, may exacerbate the negative impact of caring on the mental health of caregivers. Financial resources have been discussed as one type of coping resource. For example, in their discussion of the mediators of stress and coping, Folkman, Schaefer and Lazarus (1979) suggested that utilitarian resources, such as money, greatly increase the coping options available to any person. One study reported that being middle class with few financial worries appeared to buffer the effect of stressful behaviour for mothers of children with severe learning difficulties (Quine & Pahl, 1991). Schofield et al. (1998) concluded that financial difficulties were associated with poorer well-being in the caregivers surveyed in Victoria. The variables that were associated with increased depression in the review of research on dementia caregivers included low income or low financial adequacy (Schultz et al., 1995). In a study of parents of children with developmental disabilities, the adequacy of money and time resources had significant negative correlations with depression / demoralisation (Herman & Marcenko, 1997).

Social support

Social support can be provided both informally, by family, friends, neighbours, social groups and so on, and formally, by professionals and agencies (Dunst, Trivette & Deal, 1988). There is some evidence in the literature that the amount and quality of social support available to caregivers is an important factor in moderating the impact of caregiving. Data from the Victorian Carers Program research indicate that caregivers who reported having larger informal support networks reported greater life satisfaction, greater perceived support from family and friends, and less resentment and anger than did caregivers reporting smaller informal support networks (Schofield et al., 1998). In a study by Dunst, Trivette and Cross (1986), satisfaction with 18 sources of social support, both formal and informal, was significantly related to emotional well-being in parents of children with disabilities.

However, other researchers have reported some inconsistencies in the mediating role of social support (Baronet, 1999). There is evidence that it is the quality of social support rather than the quantity available that is most important (Deal, McWilliam, Cooper & Trivette, 1989). This finding may in part explain some of the inconsistencies in the literature.

Coping strategies

A useful definition of coping was provided by Turnbull and Turnbull (1993): "The term coping refers to the things people do (acting or thinking) to increase a sense of well-being in their lives and to avoid being harmed by stressful demands" (p. 11). The literature shows that caregivers use a broad range of coping strategies (Lundh, 1999; Nolan et al., 1996), and that there are indications that some strategies are more successful in some situations than in others (Olshevski, Katz & Knight, 1999). It has been suggested that caregivers' capabilities in coping with stresses change over time (Lefley, 1997), and that different coping strategies are used at different stages of caregiving (Nolan et al., 1996). The use of escape-avoidance as a coping strategy has been associated with increased depression in parents of children with autism, while confrontive coping has been associated with reduced depression (Dunn et al., 2001). Avoidance coping has also been significantly associated with depression

in caregivers of persons with dementia (Haley, Roth, Coleton, Ford, West, Collins & Isobe, 1996). Research on caregivers of children with a severe disability found that caregivers with greater distress and lower self-esteem used emotion-focused coping strategies more often, while those with higher self-esteem used more task-focused coping methods (Hoare et al., 1998).

Sense of mastery or self-efficacy

One of the coping resources described by Folkman et al. (1979) is general or specific beliefs, which include a sense of mastery or self-efficacy and religious beliefs. Low levels of self-esteem and mastery were associated generally with increased depression in the review of caregivers of persons with dementia (Schultz et al., 1995). In a study by Avison et al. (1993), the buffering role of mastery was found to differ between different groups of caregivers. Enhancing a sense of mastery or self-efficacy empowers individuals and is therefore a particularly sustainable type of support.

Conclusion

We have presented an overview of the impact of caring on the mental health of caregivers. Information on the experience of caregiving, and the factors associated with the impact of caregiving provides a context within which to examine what type of interventions are appropriate in various situations. Given the numerous factors that affect the impact of caring on caregivers, it is not surprising that evaluations of interventions aimed at supporting caregivers have produced inconsistent results in terms of the interventions' effectiveness (Bourgeois, Schulz & Burgio, 1996; McNally, Ben-Shlomo & Newman, 1999).

Factors such as the type of disability of the care recipient and where the caregiver is in the caregiving process will affect the impact caring has on the caregiver's mental health, and thus the type of supports most appropriate for the caregiver. The important role of moderators of the impact of caring, such as the caregiver's financial situation and coping strategies used, should also be considered by service providers when planning how to assist caregivers. Greater consideration of some of these factors may assist in more efficient use of the resources available to support caregivers. Attention should be paid to the individual situation of each caregiver. Careful assessment of caregivers' needs should consider the factors associated with a negative impact of caregiving and of the various mediators of this impact. It is also important to acknowledge the positive aspects of the caring role to ensure that these are not obstructed by interventions to assist caregivers. Global responses to the needs of all caregivers will not provide the most benefit to individuals.

While the importance of practical assistance, such as financial or respite services should not be overlooked, other avenues for supporting caregivers should be examined. Empowering individuals by helping them make the most of available sources of social support, providing assistance with coping strategies and enhancing feelings of mastery or self-efficacy may be particularly worthwhile for some caregivers, but are not currently part of mainstream services.

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