

A Review on the Outcome of Informal Caregiving on Disabled Family

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ABSTRACT

As the aging population increases, the demand for informal caregiving is becoming an ever more important concern for researchers and policy-makers alike. However, caregiving may be experienced as stressful and is associated with adverse health consequences, therefore relationship between caregiver and recipient is being elaborated. While quite a lot of research focuses on caregiving for community-dwelling older adults, this paper reviews current research on its impact on health, and family.

Keywords: Informal Caregiving, disabled families and Policy-makers

INTRODUCTION

Informal caregiver typically is a person who provides some type of unpaid, ongoing assistance with activities of daily living or instrumental activities of daily living to a person with a chronic illness or disability [1]. This is in contrast to formal caregivers, such as home health aides, who are paid for their professional services. Different studies, however, vary in their methods for defining who qualifies as a caregiver and for measuring and confirming the types of assistance provided. Our country is in the early stages of an unprecedented explosion in the number of older adults who will be living at home with physical disabilities or serious cognitive impairments. The need to provide adequate care to these vulnerable older adults is a major challenge facing our society on many levels. The assumption of our current health care system is that close family members will provide the majority of day-to-day assistance and manage the wide array of problems that confront these older adults with disabilities [2]. However, most health care delivery models focus primarily on individual patients and do not properly engage, educate, or support family caregivers or other informal care providers. For those who take on caregiving roles, the prevailing view from the research literature, public policy

statements, and the lay public is that becoming an informal caregiver for a disabled family member is often a chronically stressful experience that can become overwhelming and may even become hazardous to the caregiver's own health. Meta analyses and other systematic reviews typically conclude that caregivers are more likely to experience depressive symptoms and have poorer physical health outcomes when compared with various samples of noncaregivers [3].

Disability places a set of extra demands or challenges on the family system, most of these demands last for a long time. Many of these challenges cut across disability type, age of the person with the disability, and type of family in which the person lives [4]. The disability can consume a disproportionate share of a family's resources of time, energy, and money, so that other individual and family needs go unmet. Families often talk about living "one day at a time." The family's lifestyle and leisure activities are altered. A family's dreams and plans for the future may be given up. Social roles are disrupted because often there is not enough time, money, or energy to devote to them [5].

The basic objectives is to re-examine the outcome of informal caregiving on

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disabled families, focusing in particular on one commonly cited claim that family caregiving is associated with an increased risk for mortality.

The Nature and Extent of Informal Caregiving

Caregiving is routine and ongoing. It arises out of a relationship with the recipient in response to the need for support which is greater than normally expected due to impairment in functioning [6]. Because lower levels of caregiving merge into normal relationship reciprocity, and because it is outside any formal agreements, it is relatively invisible. Prevalence surveys in Australia, the UK and Canada have estimated that about one household in twenty has a primary caregiver, that is, a caregiver who feels responsible for the person cared for. Although both men and women are involved in caregiving, women predominate in both the numbers involved and the nature of their contribution [7]. Resident caregiving commonly involves a heavier caregiving commitment than those caregivers who live separately from the recipient of care. Our knowledge of the prevalence of informal caregiving in New Zealand is limited. Census data suggests that residential care was given by 5.4 per cent of the population and extra-residential care was given by 5.9 per cent, with the more women involved than men [8]. These figures are not directly comparable with overseas studies because they do not distinguish between temporary and ongoing incapacity. Informal caregivers assist with the tasks that recipients are unable to do for themselves. These may involve undertaking personal care household, financial and administrative tasks, providing assistance with mobility, along with emotional support and companionship. Caregiving may also include some nursing. The caregiver role varies with the age and nature of the impairment of the recipient, but is likely to involve the caregivers taking responsibility to ensure the well-being of that person. This often includes ongoing monitoring, liaising with formal care

Memmott and Thomas systems, and attending to any shortfall not provided by paid health care workers [9]. The policy context Caregiving arises in the context of relationships within families. These relationships have multi-directional patterns of exchange that interweave informal caregiving. Informal caregiving is intrinsically bound to notions of family and is subject to the demographic changes that affect families. Caregiving in part arises out of societal expectations of family and the obligations of family members to one another. Informal caregiving as an issue has moved into the policy spotlight over the last three decades in response to research revealing that informal caregiving can place a heavy burden on those involved, feminist concern that this burden falls disproportionately on women, and debate over whether the care of those with long term disability should be primarily a public cost or a private one. Research by demographers has indicated that there remain strong reciprocity patterns in New Zealand families which are based on choice rather than prescription [10]. While family cultural patterns help ensure caregiving occurs, there are increased pressures on caregivers, particularly women, who combine traditional family obligations with paid work. The pool of people available to provide care is declining because of smaller families, more family break-down, more blended families making family management more complex, and more women participating in the workforce. At the same time, the need for care is increasing due to the ageing population and the importance now placed on enabling those with disabilities to participate fully in community life.

Impacts of Caregiving

Caregiving almost always impacts on the life of the caregiver. Those heavily involved in caregiving, experience profound and wide-ranging changes to their lives. In studies that compare caregivers with others, caregivers often report poorer physical health and higher use of medication than others. In many

studies caregiving is associated with increased rates of depression and anxiety, less life satisfaction and a feeling of being burdened [11]. There is some evidence to suggest cognitive impairment and mental illness in the recipient are more burdensome for caregivers than physical problems. In general, impacts on a caregiver's mental health become greater as the time spent on caregiving increases. Being a co-residential caregiver are both factors associated with increased mental health impacts. Caregiving is associated with financial impacts including direct costs, the financial consequences of decisions around caregiving, and the constraints on choices arising from the financial status. There are often significant and multiple costs arising from caregiving [12]. Depending on the nature of the recipient's disabilities, there may be increased heating, medical costs, transport costs and house modifications. Caregivers may choose to reduce hours or withdraw from paid employment to manage caregiving responsibilities. Those supported by income maintenance find it insufficient. Low income reduces the options for support with the caregiving burden. Caregiving most commonly occurs in the wider context of the family. The effect on the family depends on the age of the recipient and the relationship of recipient to the rest of the family. However, all caregiving affects the allocation of time and attention among family members, for example by reducing time for family social activities. Parental caregivers of children with disabilities juggle the needs of other siblings with those of the child needing care. The recipient of care may also have behavioral problems which directly impact on other children. Strain between parents is reported to be common [7]. Caregivers of older people sometimes come into conflict with other family members if they express disappointment with their caregiving contribution. Caregivers commonly experience a loss of social contact with others, which is concerning given that social support has been identified as protective against the

strains of the caregiving role. Caregivers have lower participation rates in the workforce compared to non-caregivers of the equivalent age range. Women are more likely to reduce hours of paid employment compared with men [3]. Co-residential caregivers are more likely to reduce paid employment than those not living with the recipient. Caregivers used various strategies to try to fit employment with caregiving, including changing to a less demanding job, moving closer to work, and using lunchtimes, holiday leave and sick leave for caregiving purposes.

Employers can create caregiver-friendly work-places by: [5]

- Providing access to a private telephone
- Offering flexible hours and opportunities to work at home
- Providing career breaks
- Promoting supportive work relationships.

The responsibility of caregiving raises issues for the caregiver around planning for their recipient's future. Parents of children with high and complex needs may experience difficulties in planning for their child's future, especially when prognosis is uncertain. Grandparents who are caregivers may worry about living long enough to support their grandchild through to adulthood [8]. Caregivers of adults with disabilities and of older people may also worry about what would happen if they were no longer be able to care for the recipient. Despite the demands of caregiving, reviewed literature show that most caregivers provide care gladly and feel positively about the role. However, those who have heavier caregiving commitments are more likely to feel negatively. The quality of the prior relationship between caregiver and recipient influences how positively caregivers perceive their role. Caregivers of those with physical health problems are more positive than caregivers of people with cognitive issues, but caregiver satisfaction is otherwise unrelated to characteristics of the

recipient. All caregivers are more positive when they have help from others [10].

The Relationship Between Caregiver and Recipient

Caregiving is strongly grounded in the relationship between caregiver and recipient. This relationship is dynamic and evolving. The relationship commitment means it is unthinkable for many would-be caregivers to do other than care for their family member regardless of the personal cost involved [11]. For caregivers of the elderly, caregiving commonly arises out of:

- Desire to continue the relationship
- Choices for the recipient's wellbeing
- Sense of duty
- Cultural/ community/ family expectations which the caregiver has internalised.

Caregivers' motivations within, and responses to, caregiving have been found to contain a dynamic fluctuation between commitment, dissociation, obligation and repudiation. Caregiver satisfaction is closely aligned to dimensions of relationship. A positive previous relationship between the caregiver and recipient may reduce some of the strains of caregiving [2]. The caregiving

Caregiver needs and capacities are strongly influenced by caregiver characteristics, the specific needs of care receivers, and the context in which care giving is provided. That context includes the extent to which care is shared with other family members or friends (in small or large, close or dispersed networks, that function effectively or with difficulty in meeting the needs of one or more care

relationship evolves in response to the health and wellbeing of the recipient. Changes in the relationship may mean caregivers have to adopt new roles. And loss of previous familiar roles can cause feelings of grief and loss for the caregiver. Caregivers who care for more than one person in the family develop relationships based on exchange and transactions. These dynamics can cause complications in the larger family context. Other relationship issues for caregivers include:

- Internalised societal attitudes to disability acting as a barrier to the recipient of care participating equally in the relationship
- Power imbalances created by caregiving
- Caregiver abuse and neglect arising out of caregiver stress, social isolation and (sometimes) psychopathology of the caregiver
- Financial issues
- Increased risk of distress and depression for caregivers of spouses

Styles of response to issues vary, which has implications for interventions considered [5].

CONCLUSION

recipients and the primary caregiver). The fact that caring, care needs, and care resources changeover time and require adaptation must also be considered. Appreciating how public policies, workplace practices and supports, alternative housing options, and health and human services can support care givers is timely, as is continued research on caregiving across the life course.

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