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Give me a break!
Informal caregiver attitudes towards respite care

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Abstract

Background/objective: Because informal health care is now recognized to be indispensable to health care systems, different forms of respite care have been developed and publicly funded that supposedly alleviate caregivers' perceived burdens and help prolong the care giving task. Nonetheless, the use of respite care services is low even among substantially strained caregivers. To throw light on this low usage, this paper explores the associations between attitudes towards respite care, characteristics of the care giving situation, and the need and use of respite care.
Method: The survey, administered to a sample of 273 informal caregivers, addressed caregiver, care recipient, and care giving situation characteristics, as well as the familiarity and use of respite care services. It also included a sub-set of 12 statements eliciting attitudes towards respite care from an earlier study [Van Exel NJA, De Graaf G, Brouwer WBF. Care for a break? An investigation of informal caregivers' attitudes toward respite care using Q-methodology. Health Policy 2007;83(2/3):332–42]. Associations between variables were measured using univariate statistics and multinomial logistic regression.
Results: We found three caregiver attitudes, distributed fairly equally in the sample, that are apparently associated with caregiver educational level, employment status, health and happiness, as well as care recipient gender, duration and intensity of care giving, relationship, co-residence, need for surveillance, and subjective burden and process utility of care giving. However, the relation between attitude and familiarity with and use of respite care services is ambiguous.
Conclusions: Although further exploration is needed of the mix of Q-methodology and survey analysis, the overall results indicate that a considerable portion of the caregiver population needs but does not readily ask for support or respite care. This finding has important policy implications in the context of an ageing population.

Keywords: Informal care; Respite care; Consumer perspective; Q-methodology; Mixed methods

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1. Introduction

Informal care is an integral and indispensable part of most health care systems because significant proportions of the population spend considerable time

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providing care to a loved one (e.g. partners, children, and parents). In addition, given the increasing pressure on health care budgets as Western populations age, the demand for informal care is expected to rise in the coming years. At the same time, the (relative) number of people able and willing to provide informal care will probably decline as a result of demographic and socio-cultural trends like population ageing, emancipation and the increasing labour participation of women, changing family structures and increasing regional dispersion of families (e.g. [2–6]).

Even though many caregivers derive positive utility from providing care to a loved one, becoming a caregiver can have a profound impact on all dimensions of daily life. Therefore, many caregivers experience the care giving task as a substantial burden that is structurally more demanding than their support capacity, particularly when combined with other activities and role obligations [5,7–13]. Not only has this substantial caregiver burden been associated with physical, emotional, and social problems, it has been shown to be an independent risk factor for morbidity and mortality among elderly caregivers [8,14–17]. As a result, many caregivers need support to maintain their care giving role [8,18–20], and substantially strained caregivers who remain without support are at risk of burnout, which leads potentially to the ‘double boomerang’ effect of one patient’s receiving informal care eventually leading to two patients dependent on formal care.

Even though several studies have demonstrated the potential benefits of respite care for caregivers, and policy makers and health professionals appear increasingly aware of its existence and importance, the use of available respite care services is low even among substantially strained caregivers [21]. Therefore, this analysis explores why carers are not seeking or receiving such support.

2. Preliminary research and objectives

The current study is a follow-up to two previous studies of Dutch informal caregivers, one exploring caregiver attitudes towards respite care [1] and the other, the demand and use of respite care [21]. As these studies are of direct relevance to the current analysis, both are outlined below.

2.1. Attitudes towards respite care

This first study investigated caregiver attitudes towards respite care using Q-methodology [1], a mixed qualitative–quantitative method for studying subjectivity that is rooted in factor analysis. Specifically, respondents were asked to rank 39 cards containing statements on motivation for providing informal care; support capacity; physical, psychological, practical, financial, relational, and social obstacles; subjective burden; need for support; support experienced; and propensity and impediments to using respite care (see Appendix A). Caregiver attitudes towards respite care were identified through the extraction by factor analysis of patterns in the statement orderings.

The study identified three primary attitudes among three groups of likeminded individuals: caregivers who need and ask for respite care, caregivers who need but will not ask for respite care, and caregivers who do not need respite care. Caregivers who need and ask for respite care experience a substantial burden and sometimes prefer that someone else take over their task occasionally (or indefinitely). However, even though they seek such opportunities, they appear to have problems communicating their needs and desires. As a result, they often feel misunderstood and undervalued by health and welfare organisations and thus experience problems securing respite care. Caregivers who need but will not ask for respite care also experience a substantial burden and need for support but are not likely to seek it themselves. Some such caregivers derive considerable satisfaction from care giving, others feel it is their responsibility, are convinced that they are the best person to look after their loved one or view relinquishing (even part of) the care as personal failure that lets the loved one down. They are therefore reluctant to hand over the task. In other cases, care recipient resistance is the primary reason for not demanding support. That is, some care recipients have a strong preference for being cared for by a specific individual and sometimes exercise psychological pressure on their primary caregiver to maintain the care giving task. Finally, caregivers who do not need respite care derive satisfaction from care giving, enjoy sufficient support from other caregivers, and appear to manage quite well. As a result, they indicate no need for (additional) support apart from an occasional display of sympathy and concern.