Original Article

Informal Care and Home-Based Palliative Care: The Health-Related Quality of Life of Carers

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Abstract

Health is an important factor in the capacity of family and friends (informal carers) to continue providing care for palliative care patients at home. This study investigates associations between the health-related quality of life (HRQOL) of current informal carers and characteristics of the carers and their caregiving situation, in a sample of Australian carers of palliative care patients. The cross-sectional study used the Short Form-36 Health Survey to measure HRQOL. It found carers to have better physical health and worse mental health than the general population. Of 178 carers, 35% reported their health to be worse than it was one year ago. Multiple regression analyses found that the HRQOL of carers whose health had deteriorated in the previous year was associated with the patient's care needs but not the carer's time input, unlike the carers reporting stable health. Clinicians caring for palliative care patients should be alert to the potential health impairments of informal carers and ensure that they are adequately supported in their caregiving role and have access to appropriate treatment and preventive health care. J Pain Symptom Manage 2010;40:35–48. *© 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Informal care, quality of life, palliative care

Introduction

Although many palliative care services aim to help patients to stay at home for as long as possible, this relies on the availability and capacity of family and friends to provide care (informal carers). Health is an important factor in the capacity of informal carers to continue providing care.[1] Identifying the carers at risk of health problems would enable clinicians to provide appropriate support to

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prevent the development of new health problems or the exacerbation of existing conditions and better equip them to continue their caregiving role.

There is a vast literature investigating the health of carers, and meta-analyses have found carers to have worse mental and physical health than noncarers.[2,3] Conversely, in a longitudinal population study of heterogeneous carers, O'Reilly et al.[4] found carers to have a lower risk of mortality than noncarers after adjusting for baseline health status. There is evidence that, among older populations, healthier people are more likely to become carers,[1] but this was not found to be the case among middle-aged women.[5] Edwards et al.[6] found carers younger than 65 years to have worse self-reported mental and physical health than the general population, but this was not the case for those older than 65 years. These contradictions suggest that there might be vulnerable subgroups of carers rather than universal health impairment associated with caregiving and that caregiving and its impacts may vary at different life stages.

Studies have found that carer health is associated with aspects of the caregiving situation. In a population sample older than 65 years, Schulz and Beach[7] found an increased risk of mortality among carers reporting caregiver strain. Pinquart and Sorensen[8] found that psychological distress (measured as depressive symptoms and burden) had a larger negative association with caregiver physical health than sociodemographic characteristics, caregiving stressors, and resources. Caregiving stressors negatively associated with caregiver health included time in the caregiving role, care-recipient cognitive impairment, and care-recipient behavior problems; the last was the largest of these effects. The resources associated with better carer physical health included carer education and income and the availability of informal support. Physical health was also worse for older, coresident, and nonspousal carers.[8]

In the palliative care context, there is research suggesting an impact on mental but not physical health.[9,10] Conversely, Weitzner et al.[11] found that carers of cancer patients receiving curative and palliative care had similar mental health scores but that the palliative care carers had worse physical health. There is also evidence of associations with aspects of the caregiving situation for carers in the palliative care context. Brazil et al.[9] found that, in bereaved carers, poor physical health was associated with increasing age and with a greater disruption of usual activities by caregiving, whereas poor mental health was associated with insufficient family support and the patient dying in an institutional setting. Schulz et al.[12] found that strained carers had higher levels of depression and worse health practices than noncarers and carers reporting no strain; after bereavement, the depressive symptoms did not increase for the strained carers, and their health practices improved.

Vitaliano et al.[3] proposed a theoretical model for the physical health effects of caregiving as the consequence of a response to stress, which may be modified by vulnerability and resources. Pinquart and Sorensen[8] suggested four potential pathways to physical health impacts of caregiving: 1) muscular strain or skeletal injury because of physical exertion; 2) negative changes in health-related activities, such as diet and exercise; 3) the physiological effects of psychological distress; and 4) changes in sympathetic arousal and cardiovascular reactivity. For their meta-analysis of correlates of the physical health of carers,[8] they considered variables in terms of sociodemographic characteristics, caregiver stressors, caregiver resources, and psychological distress.

Much of the evidence for associations between caregiving and health comes from studies of caregiving in the aged-care context. To the extent that aged care encompasses end-of-life care, there will be considerable overlap with the palliative care context. There are also likely to be differences in that the palliative care context also will include the carers of young and middle-aged patients, the caregiving is expected to be of a shorter duration, and the proximity to death may be a motivating factor for carers to continue providing care when it may not be in their interest to do so.

In addition to the emotional demands of caregiving in the context of anticipated death, the illness trajectory and rate of decline and functional loss of the care recipient will differ between aged care and palliative care, particularly cancer palliative care. Three main trajectories have been described for people with a terminal illness, associated mainly with