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How do informal caregivers of patients with cancer cope: A descriptive study of the coping strategies employed

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ABSTRACT

Purpose: A trend exists towards moving from the hospital and caring for the patients with cancer at home, which has directed the burden of caring to the family. As a result the numbers of informal caregivers, who assumed the care of their loved ones, has increased rapidly. The aim of the study is to explore the ways that families use to cope with the stressors and hardships of caregiving and expand the knowledge about coping.
Methods: This is a descriptive research design, with the use of a convenience sample of 130 dyads. Consenting patients identified their primary family caregiver who was asked to participate in the study.
Key results: The majority of the caregivers employed emotionally focused ways of coping with the caregiving burden such as: “I was hoping for a miracle” (mean 2.19), “I was hoping that time would change things and simply waited” (mean 2.14) and “I found consolidation in my faith to God” (mean 2.05). Assertive ways of coping such as “I expressed my anger to the patient” (mean 0.78) and “I dared to do something risky” (mean 0.98) were less likely to be used by the caregivers.
Conclusions: Findings are consistent with those of previous research that informal caregivers experience substantial psychological morbidity in the form of depression in addition to caregiver burden when they assume the role of the informal caregiver. Caregivers employ various strategies in order to cope with the strains associated with the complex physical and emotional demands involved in caring.

Introduction

During the late 1980s and throughout the 1990s substantial reforms took place in the health care systems across the Western-world, introducing a trend towards moving out of the hospital and caring for the patients with cancer at home. These reforms resulted in a reduction in the number of hospital beds per capita and in the length of hospital stay (Papastavrou et al., 2009) and placed an increased pressure on families to care for their cancer relatives at home. This means by definition that the role of the informal caregiver is taken by the parent, the child, the spouse or the brother or sister. For the purpose of this study, an informal (family) caregiver is considered anybody “who provides unpaid or arranges for paid or unpaid help to a relative or friend because they have an illness or disability that leaves them unable to so some things for themselves or because they are getting older” (Gould, 2004: 18).

Data show that a significant number of the 10 million cancer survivors in the United States were cared for by a family caregiver (Teschendorf et al., 2007). There are no statistics about the care provided by informal caregivers to patients with cancer in Cyprus; however, based on statistics for informal caregivers of dementia patients, it is estimated that up to 90% of the patients with cancer receive care by a family caregiver at home. These numbers introduce a vigorous basis to better understand how informal caregivers manage, and how they can be assisted in their caregiving roles.

The literature provides an abundance of research on the numerous challenges encountered by informal caregivers of patients with cancer (Papastavrou et al., 2009, 2007); however, limited research has been conducted on the coping strategies used by family caregivers (Northfield and Nebauer, 2010). This study comes as a response to this gap in the literature. The aim is to identify what strategies informal caregivers of patients with cancer employ in order to cope with the burden of caregiving. Coping has been defined as "those changing cognitive and behavioural efforts developed for managing the specific external and/or internal demands judged as exceeding or surpassing the individual's own resources" (Lazarus and Folkman (1984: 164). The theoretical

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framework of this study is based on the stress and coping theory introduced by Lazarus and Folkman (1984) which emphasizes that there are two major functions of coping, problem-focused and emotion-focused. The function of problem-focused coping is to change the troubled person-environment relationship by acting on the environment or oneself. The function of emotion-focused coping is to change the meaning of what is happening, which mitigates the stress even though the actual conditions of the relationship have not changed.

Informal caregivers of patients with cancer tend to use both types of strategies to combat most stressful events. For example, in a quantitative study by Canadian researchers Chapman and Pepler (1998) examined the relationships between general coping style, hope, and anticipatory grief. The authors found a moderate relationship between these variables for family members of palliative care patients. Hope correlated with confrontive coping, which is described as problem-solving and provided an incentive for constructive coping with loss. Steele and Fitch (1996), explored the use and effectiveness of coping strategies employed by family caregivers of patients with terminal cancer. The participants used coping strtategies such as keeping busy, thinking positively, and learning more about the problem abd found that talking the problem over with family and friends as an effective coping strategy.

In an interpretive descriptive research, 29 active family caregivers were interviewed about the coping strategies used and the perceived factors that influence their ability to cope (Stajduhar et al., 2008). The researchers reported that the three most prominent ways of coping reported by the family caregivers were: (a) planful problem-solving; (b) seeking social support; and (c) self-controlling. The participants identified 5 factors that influenced their ability to cope including: (1) the caregiver's approach to life, (2) the patient's illness experience, (3) the patient's recognition of the caregivers' contribution to his or her care, (4) the quality of the relationship between the caregiver and the dying person, and (5) the caregiver's sense of security.

A randomized controlled trial by McMillan et al. (2006) with three groups of 354 family caregivers of community hospice patients with advanced cancer demonstrated the positive outcomes of problem-focused coping strategies. The researchers claim that the group trained in problem-solving strategies had improved caregiver quality of life and also lower burden related to patients' symptoms and caregiving tasks compared to the other two groups that received training in emotion-focused strategies or no training. Similarly, problem-focused coping strategies have been positively effective for caregivers of patients with cancer (Houts et al., 1996) and cancer patients (Sobel and Worden, 1982).

The aim of this study was to examine the type of coping strategies, the levels of burden and depression and the relationship between these variables among family caregivers of patients with cancer in Cyprus. It was hypothesized that emotion-focused coping strategies would be associated with increases in the level of burden, and problem-focused behavioral strategies would be associated with decreases in burden and depressive symptomatology.

Methods

Research design and access into the field

This is a descriptive research design, with the use of a convenience sample that is typical in family caregiving research. Ethical approval was obtained from the ethics committee of the Ministry of Health, as well as from the oncology units' management boards. The caregivers willing to participate in the study signed an informed consent. Throughout the study, measures were taken to ensure their anonymity and confidentiality.

Sample

The eligibility criteria for the caregiver included the absence of a physical or mental disability that would affect a caring role, speaking Greek and living with the patient in the same household, so as to guarantee involvement and caregiving responsibilities. Consenting patients identified their primary family caregiver who was asked to participate. The patients were treated at two oncology day-care centers and were diagnosed with cancer within the last five years. Two hundred families were approached and the final sample consisted of 130 dyads, giving a response rate of 65% and the reasons for non-participation are not known. Data were collected by two registered nurses who met the caregivers at their visit to the day-care centre. The questionnaire included demographic questions followed by the caregivers' subjective opinion about their ill relative's general health with a rating from 1 (very good) to 4 (serious health problems). Caregivers were also asked to report their source of support (i.e voluntary cancer organizations, home care organized by the state or the private sector, the family, friends or home help). The family's sources of information regarding their patient's care were also examined, to see if these were provided by doctors, nurses or others, or if caregivers did not receive any information at all. All the scales were self completed by the caregivers while waiting and nurse researchers were around to give explanations in case they were asked and also to collect the questionnaires.

Measures

Caregiver burden, emotional wellbeing in the form of depression, and coping with caregiving, were assessed with three instruments translated from English to Greek and validated in previous studies (Papastavrou et al., 2007). Validation analyses were performed and internal consistency was derived for each scale in the present study as well.

The Greek version of the ways of coping questionnaire (WCQ)

This instrument is based on the original questionnaire (Lazarus and Folkman, 1984). The Greek translation consists of 38 items, with a 4-point Likert scale, ranging from 0 to 3, to indicate the participant's frequency of using each strategy. A previous study showed internal reliability of $\alpha = 0.73$ and factor analysis produced five factors that explained 32.3% of the variation (Karademas, 1998). These were: positive approach, seeking social support, wishful thinking, avoidance strategies and assertiveness.

The caregiver burden scale (Zarit et al., 1980)

Caregiver burden was assessed using the Greek version of Burden Interview (BI) (Zarit et al., 1980; Papastavrou et al., 2007) that was designed to assess caregiver burden of elderly and dementia patients, but it has also been used in cancer caregiving research (Goldstein et al., 2004; Grunfeld et al., 2004; Higginson and Gao, 2008). This is a 22-item index, where the responses on each item are rated on a Likert scale from 'never' (0) to 'nearly always' (4).

Center for Epidemiological studies—depression scale (CES-D)

The CES-D is a 20-item scale, with a Likert scale from 0 to 3 for each item, used to assess the overall level of depression experienced in the past week (Radloff, 1977). Psychometric properties have been shown to be strong in many studies, including the translated Greek version (Madianos et al., 1992). The CES-D has been used more extensively in cancer caregiving research. (Given et al., 2004; Kim et al., 2007; Stetz and Brown, 2004).