Social Science & Medicine 60 (2005) 2321–2332

SOCIAL SCIENCE & MEDICINE

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Quality of life and coping strategies among lung transplant candidates and their family caregivers☆

Larissa Myaskovsky[a,*], Mary Amanda Dew[a,b,c], Galen E. Switzer[a,d,e], Mary L. McNulty[a], Andrea F. DiMartini[a], Kenneth R. McCurry[f]

[a]*Department of Psychiatry, Suite 502 Iroquois Building, 3600 Forbes Avenue, Pittsburgh, PA 15213, USA*
[b]*Department of Epidemiology, Suite 502 Iroquois Building, 3600 Forbes Avenue, Pittsburgh, PA 15213, USA*
[c]*Department of Psychology, Suite 502 Iroquois Building, 3600 Forbes Avenue, Pittsburgh, PA 15213, USA*
[d]*Department of Medicine, Suite 502 Iroquois Building, 3600 Forbes Avenue, Pittsburgh, PA 15213, USA*
[e]*Center for Health Equity Research and Promotion, VA Pittsburgh Healthcare System, Pittsburgh, PA 15240, USA*
[f]*Department of Surgery, UPMC Presbyterian, Suite C700, Pittsburgh, PA 15213, USA*

Abstract

Although numerous studies have examined coping strategies and quality of life (QOL) among patients with chronic diseases and their family caregivers, no studies have examined the reciprocal effects of patient and caregiver coping strategies on their dyad partner's QOL. Because most people who cope with stressful health experiences do so within the context of interpersonal relationships, it is important to understand the ways in which the two partners' coping strategies may reciprocally affect each other's QOL. Adult lung transplant candidates and their caregivers ($N = 114$ pairs) participated in semi-structured interviews that included measures of QOL and coping with patients' health-related problems. Multivariate, canonical correlation analyses were performed to examine unique patterns of associations between coping and QOL in patient–caregiver dyads. Better patient QOL, across multiple domains, was associated with better caregiver QOL. Multiple elements of patients' coping, including greater use of active coping and emotionally oriented coping were related to generally poorer patient QOL in psychosocial and physical domains. Similarly, caregivers who used more emotionally oriented coping had poorer QOL. There was no statistically reliable relationship between either (a) patient and caregiver use of coping strategies, or (b) caregiver coping and patient QOL. However, patients' coping strategies were important correlates of caregivers' QOL. These findings belie common clinical beliefs that family members' coping responses to patients' health are likely to affect patient well-being. Instead, patients' coping and QOL may be critical for understanding caregiver well-being, especially in the current era in which caregivers are assuming increased responsibility for providing patient care.

Keywords: Transplant candidates; Caregivers; Coping; Quality of life (QOL); USA

☆These data were presented in part at the Annual Meeting of the Society of Behavioral Medicine, Baltimore, MD, March, 2004. Funding was provided by Grant MH59229 from the National Institute of Mental Health, Rockville, MD.

*Corresponding author. Tel: +1 412 624 3373; fax: +1 412 383 4846.

E-mail address: myaskovskyl@upmc.edu (L. Myaskovsky).

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doi:10.1016/j.socscimed.2004.10.001

Introduction

Numerous studies have examined the quality of life (QOL) among patients with severe chronic diseases (Blumenauer, Cranney, Clinch, & Tugwell, 2003; Dew, 1998; Dew et al., 1997; Evans et al., 1985; Limbos, Chan, & Kesten, 1997; Stavem et al., 2000), and the QOL of their family caregivers (Bookwala & Schulz, 1996; Burgener & Twigg, 2002; Lyons, Zarit, Sayer, & Whitlatch, 2002; Williamson & Shaffer, 2001). A major consensus of research on patient–caregiver relationships is that caregiving tends to benefit the care recipient by providing him or her with necessary daily care and assistance, but places the caregiver at risk for compromised physical and mental health (Schulz & Beach, 1999; Schulz et al., 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995). This body of work, however, did not examine the reciprocal effects of patient and family caregiver coping strategies on their dyad partner's QOL.

In contrast, most research that has examined coping strategies and QOL in dyads, or family member pairs, has focused on non-clinical samples of married couples. These studies have indicated that the use of certain coping strategies for managing stressors can have major effects on partners' QOL (e.g., Cronkite & Moos, 1984; Giunta & Compas, 1993; Gruen, Folkman, & Lazarus, 1987; Pruchno, Burant, & Peters, 1997). For example, Cronkite and Moos (1984) found that respondents' use of avoidance coping strategies with stressful life events showed stress amplifying effects on the psychological functioning of their partners.

Because most people who cope with stressful health issues do so within the context of interpersonal relationships—where the behavior of one individual potentially affects the well-being of the other and vice versa—it is important to understand the ways in which coping strategies of the two partners may reciprocally affect each other's QOL. Better understanding of such effects could have, for example, important implications for the development of interventions that both strengthen patients' and caregivers' coping skills and improve their health and QOL outcomes. Thus, an essential step toward further clarification of the association between coping and QOL in the context of chronic illness involves examining the transactional relationship of coping and QOL within patient–caregiver dyads. A transactional conceptualization suggests that a patient's QOL would influence her/his caregiver's QOL and vice versa. In other words, it argues that patients and their caregivers engage in a series of transactions, which affects both people's QOL, when they both attempt to cope with the patient's health issues. This perspective derives from the work of interpersonal and systems theorists who argue that psychological and somatic health deficits (as well as potential benefits) can arise from or be maintained by patterns of interaction between the ailing person and others in their social environment (Cronkite & Moos, 1984; Feldman, 1976; Giunta & Compas, 1993; Gruen et al., 1987; Kahn, Coyne, & Margolin, 1985).

Thus, while many studies have examined the QOL among patients with chronic illness (Blumenauer et al., 2003; Dew, 1998; Dew et al., 1997; Evans et al., 1985) or the mental and physical costs of caregiving for patients with an illness (Beach, Schulz, Yee, & Jackson, 2000; Schulz & Beach, 1999; Schulz et al., 1997), and others have focused on coping and QOL within dyadic relationships, to our knowledge, none have examined these variables in tandem—namely the transactional relationship between a patient's coping strategies and QOL, on the one hand, with the coping and QOL of their caregiver in the context of chronic illness. In addition to its research relevance, this issue is also of both clinical and social importance because family members increasingly adopt key caregiving roles in the maintenance of patients' health and well being. In fact, as hospitals continue to look toward decreased hospital stays and reductions in outpatient services as cost-cutting measures, family caregivers assume growing responsibility for providing any daily care for the chronically ill (Dew et al., 2004; Schulz & Beach, 1999). Thus, it becomes critical to understand the potential impact of caregivers' manner of coping with patients' health on their own and patients' well being. Similarly, the burden of caregiving on caregivers' own QOL may be significantly affected by patients' health-related coping strategies.

Patients with end stage lung disease (ESLD) awaiting transplantation and their family caregivers present an unfortunate but opportune situation to examine the transactional relationship of patient–caregiver coping and QOL. Lung transplantation is a primary treatment option for end-stage lung disease, including chronic obstructive pulmonary disease, cystic fibrosis, primary pulmonary hypertension, and idiopathic pulmonary fibrosis (URREA, 2003). However, because the number of candidates for this procedure outstrips the number of available organs, patients face an extended waiting period for transplants (URREA, 2003). The period of waiting for a lung transplant is marked by numerous anxieties, and during this time, patients and their family caregivers must cope with numerous health-related stressors on a daily basis including decreased exercise tolerance, frequent hospitalizations, oxygen dependence, and continued weight loss (Manzetti, Ankeny, & Miller, 1997).

In the present study, therefore, we examined patients' and caregivers' levels of coping strategy use, their levels of QOL, and the dyadic relationships of patients' and caregivers' coping strategies and QOL during the pre-transplant waiting period. The key goal was to determine whether and how each person's coping