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Symptoms in the cancer patient – Of importance for their caregivers' quality of life and mental health?

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ABSTRACT

Purpose: To examine the level of symptom burden in a sample of cancer patients in a curative and palliative phase. In addition to determine a) whether the patients' symptom burden and patients' demographic variables, and b) the caregivers' demographic variables' impact on the caregivers' quality of life and mental health.
Method: This descriptive, cross-sectional study combines data from two samples. The first group consists of caregivers of hospitalized patients with cancer in the late palliative phase and the second group is caregivers of outpatients with cancer who have pain and/or use of analgesics.
Results: The main result showed that the symptom burden was close to equal when we compared the cancer patients in the palliative and the curative phase respectively. The whole sample of patients seemed extremely tired because they scored high on items capturing fatigue or weakness. They also had problems with pain and constipation. For patients having trouble sleeping, the caregivers' reported higher level of depression, whilst caregivers' gender had impact on the caregivers' anxiety. The younger the patients the more the impact on caregivers' QOL mental health.
Conclusion: In this study no significant differences were revealed when comparing symptom burden among cancer patients in different stages of the disease. Caregivers reported more depression when patients had trouble sleeping and more declined mental quality of life when patients were younger. Female caregivers reported more anxiety than male caregivers.

Introduction

Caregivers of cancer patients are suggested to be affected by different factors regarding their health and well-being during the patient's disease trajectory (Weitzner et al., 1999; Grunfeld et al., 2004; Grov et al., 2006a). The caregivers may be defined as partners, close relatives, next-of-kin, and significant others depending on their relationship to the patient (McClement and Woodgate, 1998). According to the Norwegian legal definition (Patient's right law, §3-3), the primary caregiver (caregiver) is the one defined by the patient regardless of their family connection. The caregivers are to be informed about the patient's health condition when the patient wants to share such information.

Cancer patients may experience multiple disease or treatment related symptoms (Donnelly et al., 1995). In a study of 796 consecutive patients with advanced cancer the most prevalent symptoms (≥50%) were pain, easy fatigue, anorexia, weakness, lack of energy, dry mouth, dyspnea, constipation, and early satiety. Most of these symptoms did not differ between primary cancer sites in either prevalence or severity. They were not able to correlate symptoms with disease stage or separate treatment related symptoms from cancer related symptoms (Kirkova et al., 2011a). However, a comprehensive clinical review of cancer symptom clusters showed that disease and treatment related symptoms are influenced by primary cancer site, disease stage and antitumor treatment (Kirkova et al., 2011b).

When staying at home with advanced cancer, the patient and his/her caregiver coordinates the support needs necessary in collaboration with the community oncology nurse. The impact of the involvement and responsibility during the cancer journey might leave concerns on caregivers. Studies have been performed during different stages of the cancer patients' disease trajectory, and for

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caregivers there are reported burden (Given et al., 2004; Goldstein et al., 2004; Doorenbos et al., 2007; Higginson et al., 2008), reaction in terms of particular burden and well-being (McCorkle et al., 1993; Nijboer et al., 1999; Hagedoorn et al., 2002; Grov et al., 2006c), quality of life (QOL) (Grov et al., 2005; Clark, 2006; Grov et al., 2006b), mental health (Edwards and Clarke, 2004; Grov et al., 2005), and a large number of specific aspects influencing the caregivers' situation, e.g. work and economy (Goldzweig et al., 2009), and the impact of educational level and educational programs facilitated for caregivers (Clark, 2006; Goldzweig et al., 2009). In a recent study 38% of caregivers reported depressive symptoms in the clinical range as measured by Center for Epidemiological Studies-Depression scale (CES-D) (Steel et al., 2011).

Weitzner et al. (1999) compared QOL measured by the Short form 36 (SF-36) in caregivers of cancer patients in the palliative versus the curative phase. The caregivers of patients in the palliative phase generally reported lower QOL than those caring for patients in the curative phase. The latter mentioned study suggested that caregivers' QOL was dependent on factors related to the patient's condition as well as individual characteristics of the caregiver. The main findings were that caregivers' physical QOL was dependent on the patient's performance status as well as the education level of the caregivers. They recommend research to focus on caregivers' situation in terms of QOL and emotional distress and factors influencing these variables. Others have also stated that the patients' illness characteristics may be factors that influence the families' level of depression and anxiety (Edwards and Clarke, 2004), and a study of 82 adult caregivers showed that patients' pain were significantly correlated with caregivers' depression, but they found no correlation between patients' fatigue and caregivers depression (Bush and Carter, 2004).

Cancer stage of the patients is shown as a predictor of caregivers' physical QOL in addition to health behavior and overload (Matthews et al., 2004). Besides the effect of the direct stress or burden of caring for the cancer patients, differences in caregivers' QOL may be linked to gender and partner role expectations. Stressors that have a strong effect on female family caregivers may have a weaker effect on male family caregivers and vice versa. Previous studies have indicated that female caregivers are more distressed by factors involving social and family relationships, and male caregivers are more worried about work related and financial issues (Goldzweig et al., 2009). Supportiveness, mood and partners' health condition seem to be more sternly related to female caregivers' than to male caregivers' psychological well-being (Hagedoorn et al., 2002).

Fridriksdottir et al. (2011) have studied QOL, anxiety, and depression in family members of cancer patients and found high prevalence of anxiety and depression. The latter mentioned study did not specifically report differences for caregivers when studying patients in curative versus palliative phase.

The curative phase is defined as a stage where the patients are admitted to a curative treatment intention, while the palliative phase is defined according to the definition of palliative care stated by World Health Organization (WHO) (1990) (WHO (World Health Organization) 2005) (http://www.who.int/cancer/palliative/definition/en/) and European Association for Palliative Care (EAPC) (2002) (EAPC (European Association for Palliative Care) 2005) (http://www.eapcnet.org/about/definition.html). Since Weitzner et al. (1999) have reported lower QOL among caregivers of cancer patients in the palliative phase compared to those caring for patients in the curative phase, and that explanation for the findings might be related to aspects of the patient's condition as well as individual characteristics of the caregivers, we wanted to shed light on the impact of the patients' symptoms and demographic variables in the cancer patients and their caregivers.

The aims of this study are therefore to examine;

1) The level of symptom burden in a sample of cancer patients in the curative phase compared to the palliative phase
2) The impact of patients' symptom burden, demographic variables of the patients and demographic variables of the caregivers on caregivers' QOL and mental health.

Since the symptom burden is expected to increase during the cancer trajectory, and the symptom load therefore is presumed higher in the palliative than in the curative phase, our hypothesis is that the QOL will be affected negatively by patients defined in the palliative phase, and those with high symptom load. The same argument is given for the caregivers' mental health, and we expect higher level of anxiety and depression for caregivers of patients in the palliative phase and those with high symptom load. In addition we hypothesize that female caregivers' experience higher level of anxiety and depression than men (Hagedoorn et al., 2002; Goldzweig et al., 2009).

Materials and methods

Samples

This descriptive, cross-sectional study is a secondary analysis which combines data from two different studies in which patients were recruited together with their family members. The first group of patients were recruited between February 2002 and October 2003. At the recruitment time these patients were hospitalized with cancer in the palliative phase staying in a large, tertiary referral cancer hospital in Norway, but the intention was to leave the hospital for staying at home during this part of the cancer trajectory. All patients had metastatic cancer with estimated survival time of <4 month at the recruitment time. Of the patients recruited to this study 31% died within four month following up and 63% patients were dead after one year (Grov et al., 2006b). Eligible patients and family caregivers were consecutively invited to participate and given an information letter and a consent form to complete. A total of 96 dyads consented and completed the questionnaires.

The second group of patients was recruited between January and June 2005 from outpatient oncology clinics (i.e., general, gynecology, lung, pain, chemotherapy, radiotherapy) at the same hospital as the first patient-group. All patients coming to the outpatient clinics during selected periods of time were screened for pain as one of the main purposes of the primary study was to describe cancer patients' pain prevalence (Valeberg et al., 2008). Treatment intention (curative or palliative) was assessed from the medical charts by an experienced physician. Patients with pain and their family caregivers received written information about the study and were invited to participate. A total of 73dyads consented and completed the questionnaires and is part of this study.

Patients in both studies were included if they were: >18 years of age; had a diagnosis of cancer; were able to read, write, and understand Norwegian. Patients from the first sample had to understand that they had metastatic cancer, have an estimated survival time of more than four months, an ECOG performance status $\geq$1, and to be managed at home with support from caregivers and/or health care personnel. The exclusion criterion was known mental disorder. In the second sample, all patients had self-reported pain of any intensity and/or use of analgesics. The recruitment procedure is described more thoroughly elsewhere, for the first sample (Grov et al., 2005) and for the second sample (Valeberg et al., 2008).

All patients and their caregivers provided written informed consent. This study was approved by the Regional Ethics