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# Does the cancer patient's disease stage matter? A comparative study of caregivers' mental health and health related quality of life

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## ABSTRACT

*Objective:* Cancer affects both patients and their caregivers. Caregiver burden may change during different stages of the patients' cancer trajectory. Limited research has focused on the impact of being a caregiver, assessed by the caregiver's mental health and quality of life (QOL) during the curative and the palliative phases of the patient's disease. The aim of this study is to compare caregivers of cancer patients during the curative and a palliative phases with respect to their mental health and health-related QOL.

*Method:* This descriptive, cross-sectional study combines data from two studies. The first group consists of caregivers of patients with cancer in the late palliative phase and the second group consists of caregivers of outpatients with cancer who suffer from pain and/or use analgesics. Data were collected by means of standardized measures and analyzed with descriptive statistics.

*Results:* Based on this material, no significant differences in mental health and health-related QOL were revealed for caregivers of cancer patients in the palliative and the curative phases, respectively. Neither education level in the caregivers, nor the patients' functional status influenced caregivers' mental health or QOL. Younger caregivers seem to have better physical QOL.

*Significance of results:* Being caregivers of cancer patients seems to have a similar pattern of impact on caregivers' mental health and quality of life regardless of the patient's disease stage. We share some reflections about the way in which the cancer stage is divided and the appropriateness of such selection for measuring caregivers' mental health and QOL. Additionally, we discuss the use of generic instruments for measuring specific contexts and particular samples.

**KEYWORDS:** Palliative and curative phases, Mental health, Health-related QOL, Cancer, Caregivers

## INTRODUCTION

Cancer affects not only the patient, but also the patient's relatives and significant others

experience the impact of the patient's disease trajectory (Grunfeld et al., 2004; Grov et al., 2006b). Caregiver burden changes during different stages of the patients' cancer (Goldstein et al., 2004; Doorenbos et al., 2007; Higginson & Gao, 2008). Compared with the palliative stages of the disease, caregiver reactions and burden are less during earlier stages of cancer (McCorkle et al., 1993; Nijboer et al., 1999; Grov et al., 2006c). Spousal caregivers of cancer

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patients at the end of life may be a population at risk for elevated burden (Doorenbos et al., 2007). Additionally, caregivers of cancer patients who experience treatment-related symptoms are more likely to report caregiver burden (Given et al., 2004). Other studies have focused on how the burden of cancer caregiving affects the caregivers' quality of life (QOL) (Weitzner & McMillan, 1999; Grov et al., 2005, 2006a). One study evaluated an intervention program, including physiotherapy and psycho-educative elements, showing no long-lasting effects on caregivers' QOL (Clark et al., 2006). Caregivers are vulnerable when caring for cancer patients at home. From a Norwegian study among caregivers of cancer patients in the palliative phase, the level of the mental dimension of health-related QOL (measured with the MOS Short Form 36; SF-36) is significantly lower, and the anxiety level of caregivers is significantly higher than that of the general population (Grov et al., 2005).

The connection between the content of the concepts "caregiver burden" and the "caregivers' QOL" and "mental health" might be present. However, the conceptualization and instruments suggested to measure these concepts may differ. There is a need for a more explicit definition of QOL for family caregivers (Sales, 2003; Kitrungrate & Cohen, 2006). Even within the definition of QOL there are dimensions and nuances in how to interpret this phenomenon. Spilker divides QOL into three levels in his pyramid (Spilker, 1996). The top level is global QOL and contains overall well-being and satisfaction with life as a whole. Health-related QOL might be defined as health status — components placed in the middle level — and single aspects of health-related QOL are defined as the level of specific parts of QOL in the pyramid's lowest level. Based on this conceptualization, mental health could be positioned in the lowest level, for example, by the concepts anxiety and depression.

Weitzner et al. (1999) compared QOL measured by the SF-36 in caregivers of patients in the palliative versus the curative phase. The QOL-dimension of physical health was lower among the caregivers of patients in the palliative phase compared to those responsible for patients in the curative phase (Weitzner et al., 1999). No differences were found between the groups for the QOL-dimension of mental health. The latter mentioned study suggested that caregivers' physical health 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. As to our knowledge the above mentioned study is the only one studying different phases in

the cancer caring trajectory from the perspective of the caregivers' QOL.

Cancer stage is shown as a predictor of caregivers' physical QOL in addition to health behaviour 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 closely related to female caregivers' than to male caregivers' psychological well-being (Hagedoorn et al., 2002).

Education level is another variable that may influence caregivers' psychological distress or QOL. Goldzweig et al. (2009) found that there was a negative correlation between education level and physiological distress (Goldzweig et al., 2009) and others have found that caregivers with low educational level reported low QOL (Weitzner et al., 1999).

To our knowledge, no other studies than those previously mentioned have compared the health-related QOL and level of anxiety and depression in caregivers of cancer patients in the curative and the palliative phases. The curative phase is defined as a stage in which patients are receiving curative treatment, whereas the palliative phase is defined according to the definition of palliative care stated by World Health Organization (WHO) (1990) (World Health Organization, 2005) (<http://www.who.int/cancer/palliative/definition/en/>) and the European Association for Palliative Care (EAPC) (2002) (European Association for Palliative Care, 2005) (<http://www.eapnet.org/about/definition.html>). The aim of this study is to compare caregivers of cancer patients in the curative and the palliative phases with respect to their mental health and health-related QOL.

The main research question is: Does the cancer patient's disease stages influence the caregiver's mental health and health-related QOL?

Because proximity to the patient's expected death is presumed to be a significant stressor, our hypothesis is that the health-related QOL will be higher and the level of anxiety will be lower in caregivers of cancer patients in the curative phase than in caregivers of cancer patients in the palliative phase. Based on findings from the previous study on caregivers of cancer patients in the palliative phase (Grov et al., 2005), no difference in the level of depression is expected among the two groups.

## METHOD

### Samples

This descriptive, cross-sectional study combines data from two 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 late palliative phase and were staying in a large, tertiary referral cancer hospital in Norway, but the intention was for them to leave the hospital to stay at home during this part of the cancer trajectory. Eligible patients were consecutively invited to participate and given an information letter and an informed consent form to complete. A total of 117 patients consented and returned the questionnaire. Participating patients were provided with an information letter and an informed consent form to give to their caregivers. Ninety-six caregivers consented and completed the questionnaires.

The second group of patients was recruited between January and June of 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. Patients with pain received written information about the study and were invited to participate. A total of 217 patients consented and returned the questionnaires. The family members were recruited through the patients, as patients had to consent to their participation. A total of 71 caregivers consented and completed the questionnaires.

Patients in both studies were included if they were: >18 years of age; had a diagnosis of cancer; and 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 >4 months, have an Eastern Cooperative Oncology Group (ECOG) performance status  $\geq 1$ , and to be managed at home with support from caregivers and/or healthcare personnel. The exclusion criterion was having a known mental disorder. In the second sample, all patients had self-reported pain of any intensity and/or were using analgesics. The recruitment procedure is described more thoroughly elsewhere, (for sample one, see Grov et al., 2005, and for sample two, see Valeberg et al., 2008).

All patients and their caregivers provided written informed consent. This study was approved by the Regional Ethics Committee, the Norwegian Radium Hospital's Protocol Review Board, and The Norwegian Data Inspectorate.

## Instruments and Scoring Procedures

### Demographic Data

Demographic data from patients included gender, age, marital status (married/partnered or not), educational level (primary school [i.e., up to 10 years at school], secondary school [i.e., from 11 to 14 years at school], or college/university), and employment status (working full or part-time or not working). From the caregivers, demographics included age, gender, educational level and employment status.

### Medical Record Review

Patients' medical records were reviewed by two experienced physicians to obtain information on cancer diagnosis, presence of metastasis, and whether the treatment intention was palliative or curative.

### Functional Status

In the first sample, patients' performance status was measured using The ECOG performance status assessment tool. The WHO-index (ECOG performance status) assesses an individual's ability to perform daily activities. It is categorized as a score from 0 to 4, (0 = full activity; 1 = restrictions related to physically strenuous activity; 2 = capable of self care, but unable to perform work-related activities, up and awake more than 50% of waking hours; 3 = capable of only limited self care, confined to bed or chair >50% of waking hours; 4 = completely disabled, not capable of any self care, totally confined to bed or chair) (Oken et al., 1982). Patients in the second sample reported their functional status using a modified Karnofsky Performance Status (KPS) scale that ranged from 40 (i.e., disabled, need special help and care) to 100 (i.e., adequate health status with no complaints and no evidence of disease). Reliability and construct validity of the KPS are well established and it is considered to be a global indicator of the functional status of patients with cancer (Schag et al., 1984). In order to compare patients from the different settings, patients scoring  $\geq 80$  on the Karnofsky scale were labelled as having high function, and patients scoring 40–70 were labelled impaired. For ECOG status, the cutoff was defined to be 0, and 1 represented high function whereas 2–4 represented impaired.

### Hospital Anxiety and Depression Scale (HADS)

Anxiety and depression of caregivers were assessed by the HADS. It has been found to perform well for studying mental health in the general population, in cancer patients, and in primary care patients (Mykletun et al., 2001). HADS consists of 14 items,

7 on the depression sub-scale (HADS-D) and 7 on the anxiety sub-scale (HADS-A). Each item is scored on a four-point scale from 0 (not present) to 3 (considerable), and the item scores are added, giving HADS-D and HADS-A scores from 0 (minimum symptom load) to 21 (maximum symptom load). A score  $\geq 8-10$  on anxiety or depression is defined as borderline abnormal, and a score  $>10$  is defined as abnormal (Zigmond & Snaith, 1983).

#### *Health-Related QOL: SF-36*

Health-related QOL of the caregivers was assessed by SF-36. The SF-36 contains 36 items grouped into the eight multi-item health dimensions including physical functioning (PF, 10 items), role limitations caused by physical problems (RF, 4 items), bodily pain (BP, 2 items), social functioning (SF, 2 items), mental health (MH, 5 items), role limitations caused by emotional aspects (RE, 3 items), vitality (VT, 4 items), and general health perceptions (GH, 5 items) (Ware & Sherbourne, 1992; Ware et al., 2000). The items are answered in "yes" or "no" alternatives, or in scales with three to six response alternatives. For each dimension, questions are coded, summed, and transformed to a scale from 0 (worst) to 100 (best). The SF-36 can also be divided into two component scores, physical and mental health sum-scores, named PCS and MCS.

#### **Statistical Analysis**

Data were analyzed using SPSS Version 17.0 (SPSS, Inc.). Descriptive statistics were calculated for the patients' and family members' demographics. To examine if patients' disease stage had an impact on the caregivers' mental health and health-related QOL, the samples were divided into caregivers of patients in the palliative phase ( $n = 124$ ) and caregivers of patients in the curative phase ( $n = 32$ ).

The continuous variables were examined with  $t$  tests, and categorical variables with  $\chi^2$  tests, or Fisher's exact test. Four linear regression analyses were performed with the mental and physical health components of the SF 36 and anxiety and depression respectively as the dependent variables. The independent variables used in the latter mentioned regression analysis are: caregivers' age, gender, and marital status, in addition the patients' disease stage (i.e. curative or palliative phase). Significance level was set at  $p < 0.05$ , and two-sided tests were applied.

## **RESULTS**

### **Demographics**

Demographics and clinical characteristics for the patient samples are given in Table 1. The patients'

age ranged from 23 to 86 years and the majority were married women who were unemployed or working at home. When we compared patients in the palliative phase with the patients in the curative phase, significant differences were found in age, education, marital status, cancer sites, and presence of metastases.

The majority of the caregivers were men and their ages ranged from 19 to 82 years. Approximately 50 % of the caregivers worked full time. There are statistical differences between the caregivers of patients in the two phases, as caregivers of patients in the palliative phase are more often older women who are single, compared with the caregivers of patients in the curative phase (Table 2).

Figure 1 shows the result of comparing the caregivers' anxiety and depression organized either by being caregivers of the patients in the palliative or in the curative phase. No significant differences were found, with  $p$  values of 0.44 for anxiety, and of 0.76 for depression.

Figure 2 shows that there is no significant difference in health-related QOL between the caregivers of patients in the palliative phase and caregivers of patients in the curative phase, with  $p$  values from 0.17 (physical function) to 0.95 (social function).

When we divided the SF-36 dimensions into PCS and MCS QOL sum-scores, no significant differences were shown for the caregiver groups. Figure 3 shows an overview of PCS and MCS sum-scores for caregivers of patients in the curative and the palliative phases.

As no significant differences were revealed for the eight SF-36 dimensions regarding caregivers of cancer patients in the palliative versus the curative phase, linear regression analysis were performed for the PCS and the MCS QOL sum-scores. When we examined the association between the health-related QOL sum-scores (PCS and MCS), anxiety and depression in caregivers of cancer patients in the palliative and the curative phases by means of linear regression analyses, no significant differences were found, except for caregivers' age. Younger caregivers seem to have better physical QOL (Table 3).

## **DISCUSSION**

Our main finding was equality in the mental health and level of health-related QOL in caregivers of cancer patients in the palliative and the curative phases, respectively. The initial hypothesis was therefore not supported by data from this material. In our study neither education level in the caregivers nor the patients' functional status seemed to influence caregivers' health-related QOL, which is contradictory to the study by Weitzner et al. (1999). However,

**Table 1.** Demographic and clinical characteristics of the total sample and among the two patient groups

Characteristics	Total sample	Palliative phase	Curative phase	p-value
<b>Age</b> , mean (SD)	58.6 (11.3)	60.0 (10.9)	52.3 (10.2)	0.001
<b>Gender</b> , n (%)	50 (31)	43 (34)	7 (22)	0.19
Men	109 (69)	84 (66)	25 (78)	
Women				
<b>Education</b> , n (%)				0.01
Primary school	35 (23)	34 (27)	1 (3)	
Secondary school	59 (38)	43 (35)	16 (52)	
College/university	61 (39)	47 (38)	14 (45)	
<b>Married/partnered</b> , n (%)				0.001
Yes	59 (37)	28 (22)	31 (97)	
No	100 (63)	99 (78)	1 (3)	
<b>Employment status</b> , n (%)				0.32
Not working	136 (87)	110 (88)	26 (81)	
Working full/part time	21 (13)	15 (12)	6 (19)	
<b>Function</b> , n (%)				0.35
High function	103 (65)	80 (63)	23 (72)	
Impaired	56 (35)	47 (37)	9 (28)	
<b>Cancer diagnosis</b> , n (%)				0.003
Breast	74 (46)	61 (49)	13 (41)	
Prostate	29 (18)	28 (22)	1 (3)	
Gynecologic	7 (5)	4 (3)	3 (9)	
Colorectal	20 (13)	17 (13)	3 (9)	
Other	29 (18)	17 (13)	12 (38)	
<b>Metastases</b> , n (%)				0.001
Yes	129 (81)	124 (98)	5 (16)	
No	30 (19)	3 (2)	27 (84)	

they did not find any significant difference in mental health variables on caregivers' QOL for either of the groups, which is in accordance with our results.

When we stated the research question, we expected the patient's disease stage to have impact on the caregivers' level of anxiety and health-related QOL. Several studies on caregiver burden and QOL suggest such association (McCorkle et al., 1993; Nijboer et al., 1999; Weitzner et al., 1999; Grov et al., 2006c; Doorenbos et al., 2007). Our study

reveals another possible explanation. Caregivers might experience an overall stressor of caring for a cancer patient independent of the stage of the disease the patient is at. Another way of interpreting the results from this study is that dividing patients into the palliative and the curative phase is a too rough way of defining patients' and caregivers' situations.

From Grov et al.'s (2005) study we know that the mental health dimension of the health-related

**Table 2.** Demographic characteristics of the caregivers of the two patient groups

Characteristic	Total sample caregivers	Palliative phase	Curative phase	p-value
<b>Age</b> , mean (SD)	57 (12.3)	57.7 (12.1)	52.2 (11.3)	0.002
<b>Gender</b> , n (%)				0.005
Men	102 (61)	70 (55)	32 (80)	
Women	65 (39)	57 (45)	8 (20)	
<b>Education</b> , n (%)				0.77
Primary school	37 (23)	29 (24)	8 (29)	
Secondary school	62 (38)	45 (36)	17 (43)	
College/university	65 (40)	50 (40)	15 (38)	
<b>Married/partnered</b> , n (%)				0.001
Yes	70 (42)	31 (24)	39 (98)	
No	97 (58)	96 (76)	1 (2)	
<b>Employment status</b> , n (%)				0.18
Not working	77 (47)	62 (50)	15 (38)	
Working full/part time	88 (53)	63 (50)	25 (62)	

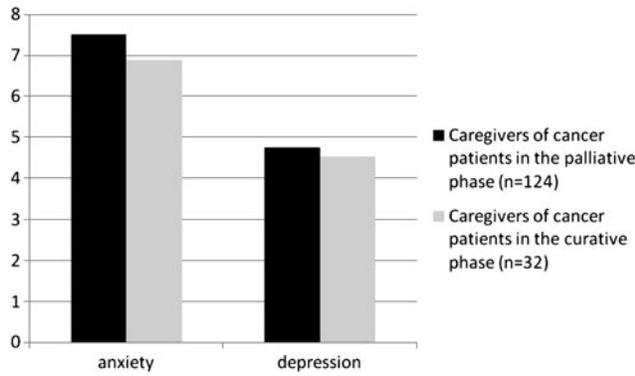


Fig. 1. Anxiety and depression in caregivers of cancer patients in the palliative and curative phases.

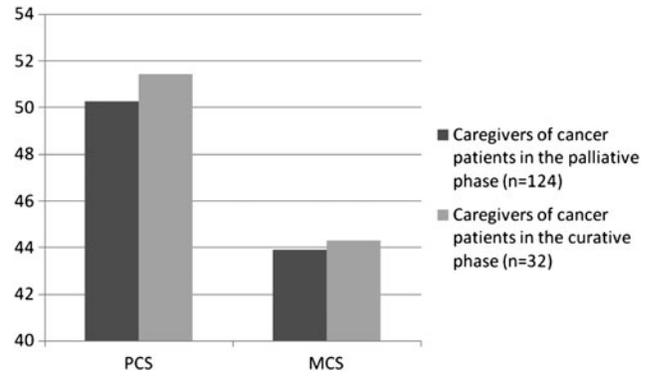


Fig. 3. Physical and mental quality of life for caregivers of cancer patients in the palliative and curative phases.

QOL, measured with SF-36, and the anxiety level, measured with the HADS, negatively affected caregivers in terms of lower health-related QOL and higher level of anxiety than the general population. However, the instruments used in this study do not incorporate the caregivers' concerns regarding the cancer patients' proximity to death, which might be one perspective of cancer caregivers' QOL. The caregivers' experience, reaction, and burden are not measured by the SF-36 and the HADS, and therefore we are not able to catch this important dimension of the caregivers' situation. The SF-36 measures functional status (e.g., being able to carry heavy things, walk distances, or use stairs), whereas the HADS measures different aspects of anxiety and depression (e.g., fear and adhenonia). In order to monitor significant impact on the caregivers' overall situation, for example, despair, struggling, hopelessness, inner strength, coping, courage, burden, and well-being, and not only functional status and distress, other instruments are suggested as being more suitable. As mentioned in the Introduction, the conceptualization of QOL is difficult (Spilker, 1996), and the way to

operationalize central concepts in various phases of the cancer trajectory, especially the palliative phase, might also reflect challenges (Kaasa & Loge, 2003).

Kitrungrote and Cohen (2006) and Sales (2003) argue for a more explicit definition of QOL for family caregivers. Such concept development might be one solution for enhanced understanding of family caregivers' QOL. However, we suggest in-depth analyses of each study's concepts and instruments selected to cover these concepts, in addition to considerations about the appropriateness of the instruments for the specific context and samples. During this process it might be possible to capture particular areas and perspectives, thereby making a relevant contribution

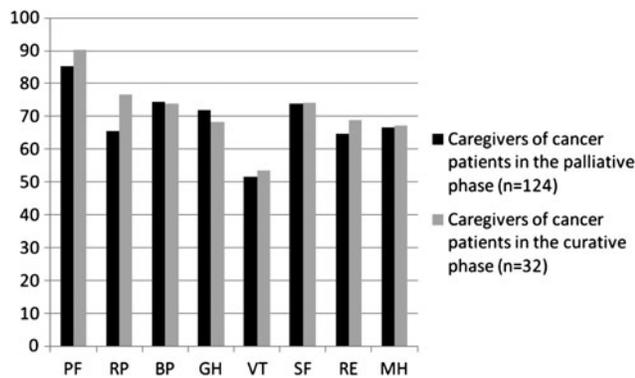


Fig. 2. Health-related quality of life in caregivers of cancer patients in the palliative and the curative phases.

Table 3. Linear regression analyses with physical and mental quality of life, anxiety and depression as dependent variables

	Std. $\beta$	$t$	$p$ -value
<b>PCS</b>			
Curative/palliative phase	0.01	0.14	0.89
Gender	0.10	1.23	0.22
Age	-0.29	-3.51	0.01
Married/partnered	0.02	-0.23	0.82
<b>MCS</b>			
Curative/palliative phase	-0.02	-0.26	0.79
Gender	0.04	0.48	0.63
Age	0.13	1.46	0.15
Married/partnered	0.01	0.07	0.95
<b>Anxiety</b>			
Curative/palliative phase	0.01	0.10	0.92
Gender	-0.09	-1.14	0.26
Age	0.06	0.75	0.45
Married/partnered	-0.05	-0.49	0.62
<b>Depression</b>			
Curative/palliative phase	0.01	0.05	0.96
Gender	0.02	0.28	0.78
Age	0.06	0.73	0.47
Married/partnered	-0.02	-0.16	0.87

to the body of knowledge within this field. Based on the material from this study, we are able to present an overall view of caregivers' mental health and health-related QOL, but not global QOL (Spilker, 1996), other aspects, or specific concerns that might be relevant to caregivers' QOL during patients' cancer trajectory.

### Strengths and Limitations

In this study, the use of standardized, psychometrically established instruments is of importance for the validity and reliability of the results. However, as mentioned previously, there is also a limitation caused by using generic instruments, because such questionnaires are not meant to reach dimensions that are specific to people in unique situations. The result from this study indicates that the measures used are not able to capture whether the caregivers' QOL in general is associated with the cancer patients' disease stage. However, the findings indicate that the health-related QOL and distress are similar between caregivers of cancer patients in the palliative and the curative phases.

Some of our non-significant results could be a result of type II statistical error resulting from the low sample sizes. We do not know the associated duration and functional impairment associated with caregivers' mental health and health-related QOL, as our study is cross-sectional.

Another problem may be that two groups of patients (i.e. patients in the palliative and in the curative phase), were drawn from two different samples. The patients were from different settings, with somewhat different inclusion criteria, and data were assessed at different times. The same analyzes as described in this study were therefore performed for the two original data sets in order to examine whether the way in which we divided the two original samples into the palliative and the curative phases could influence the result. No differences were found regarding the caregivers' mental health and health-related QOL in the original data set consisting of data from caregivers of outpatients and caregivers of patients in late palliative phase (data not shown).

### CONCLUSIONS

Health-related QOL and mental distress, measured with SF-36 and the HADS respectively, are similar among caregivers of cancer patients in the palliative and in the curative phase. The study highlights the challenge by using generic instruments when examining QOL aspects of vulnerable people in specific contexts.

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