The impact of cancer patients' and their family caregivers' physical and emotional symptoms on care giver burden

Safora Johansen[1,2] PhD, Milada Cvancarova[2,3] PhD and Cornelia Ruland[3,4] PhD

[1]Department of Cancer Treatment, Section of Radiation Therapy, Division of cancer, Surgery and Transplantation, Oslo University Hospital, Norway, [2]Department of Life Sciences and Health, Oslo and Akershus University College of Applied Sciences, [3]Center for Shared Decision Making and Collaborative Care Research, Oslo University Hospital, Norway, [4] Department of Medicine, University of Oslo, Norway

Corresponding Author:

Cornelia Ruland
Center for Shared Decision Making and Collaborative Care Research, Oslo University Hospital, Norway, Department of Medicine, University of Oslo, Norway

Sogn Arena, Klaus Torgaards vei 3A
0372 Oslo, Norway

Cornelia.Ruland@rr-research.no

Conflicts of Interest: The authors have no conflicts of interest to disclose.

Key words: Family caregiver, cancer patients, care giver burden

Abstract

Background: While there is significant evidence that Family Caregivers (FCs) of cancer patients can experience significant caregiver burden and symptoms, less is known about the relationships between FCs and patient characteristics that influence caregiver burden.

Objective: To examine the impact of cancer patients' and FCs symptoms and demographic characteristics on caregiver burden at initiation of the patients' radiation treatment.

Methods: Two-hundred-eighty-one dyads of FCs and cancer patients diagnosed with breast, prostate, melanoma, lymphoma, head and neck cancer were recruited at the beginning of the patients' radiation treatment. Measures of depression, sleep disturbance, fatigue, social support and self-efficacy were obtained from both FCs and cancer patients. FCs were also assessed for caregiver burden. Associations between patients and caregiver's symptoms and demographic characteristics and caregiver burden were investigated using multivariate analyses.

Results: There were significant associations between caregiver burden and the *patient-related* variables self-efficacy (p=.02), sleep disturbance (p= .03) and social support (p=.04). Among *FC-related* variables higher scores of depression (p<.01), fatigue (p<0.01) and symptoms (p<.01) were significantly associated with higher caregiver burden. Being a female, either as a patient or FCs increased the likelihood of experiencing fatigue and sleep disturbance.

Conclusion: Caregiver burden in FCs is influenced by an interplay of patients' as well as own symptoms and problems. These inter-dependencies exist from the beginning of treatment.

Implications for practice: Nurses should systematically assess the problems and symptoms of patients as well as FCs and support them from the time of diagnosis to help prevent symptom development and deterioration.

Introduction

The global burden of cancer continues to increase because of the aging and growth of the world population alongside cancer-related life-style behaviors in economically developing countries. Based on the global statistics, about 14 million people were in 2012 diagnosed with cancer [1]. In Norway there has been an increased incidence rate of 5.4 % in men and 4.6 % in women since 2008 [2]. Clearly, cancer touches a substantial number of individuals' lives and does not only affect the person who is diagnosed, but the entire family.

Family caregivers (FCs) are often the primary source of social and emotional support for patients, and play major roles in how well patients manage with the consequences of illness and treatment [9-10,12]. FCs of cancer patients report a number of problems related to their caregiving experiences [3-7]. Several studies have shown that FCs are exposed to considerable burden over long periods of time [8-10]. Research indicates that FCs have significantly more anxiety than the normal population, and the patients' illness can have severe impact on FCs health and quality of life (QoL) [8]. Although most research on FCs has focused on the negative experiences of providing care, studies have also reported perceived values of taking care of family members who are ill [13-17]. The degree of which FCs have negative and positive experiences of care giving, their own baseline physical and emotional condition and how they describe the caregiving burden at the time of diagnosis affect their ability to care for the cancer patient during the illness trajectory, as well as their own quality of life [18-20]. To help both patients and FCs to get through the illness in a best possible way, it is crucial to understand how FCs perceive their problems, symptoms and caregiver burden from the onset of the illness and how this relates to patients' symptoms and problems.

It is well known that cancer patients experience multiple and frequently severe symptoms. Many studies [21-25] have shown the adverse effects of cancer treatment. In addition, healthcare reforms and policies in many countries emphasize the need to support patients in taking a more active role in managing their illness [26-27]. At the same time, recent treatment-, economic and policy changes have resulted in a shift from inpatient to more outpatient care, placing a greater caregiving responsibility on FCs of cancer patients [4]. However, few studies so far have investigated the relationships between the symptoms and problems in cancer patients as well as FCs and the impact on caregiver burden.

Thus the purpose of this study was to investigate the associations between the symptoms and problems in cancer patients and FCs, and caregiver burden in FCs during / at the beginning of the patients' radiation treatment.

Material and methods

Participants and study design

This paper presents data from a larger study funded by the Norwegian Cancer Society to investigate the effects of an online support system for cancer patients and their FCs. All study procedures were approved by the Ethical Committee of the South-Eastern Norway Health authority and the Data Inspectorate of Norway.

For the study presented here, 562 cancer patients (n=281) with breast, prostate, head and neck cancers, and melanoma, lymphoma, and their FCs (n=281) were recruited at a University Hospital in Norway between 2012-2014 at the beginning of the patients' radiation treatment with curative (90%) or/and palliative (10%) intent. Cancer patients were primarily recruited at the Cancer Clinic's department of Radiation Therapy by health professionals in the department, or by members of the research team. Information about this study was also distributed through advertisements in newspapers, information leaflets and on the Norwegian Cancer Society's websites [28] with contact information about how to contact the research team if interested to participate in the study.

Patients interested in study participation were referred to the study's research assistant (RA) who provided more information about the study. At this contact, patients were screened for eligibility criteria (see below). Patients consenting to participate were asked to identify the closest person they considered as primary care giver. Participation of both the patient and the FC was a study requirement. The FC did not necessarily need to be a "family member" in the traditional sense of someone related by blood or marriage, but could also be a close friend. In this study 99% of the FCs were family members.

If the FC accompanied the patient to the clinic, they were both introduced to the study's purpose at the same time. After signing the consent forms they were asked to complete the study questionnaires described below. If the FCs were not present, the patient took home a letter for the FC containing information about the study, the informed consent form and the questionnaires. If the FCs agreed to participate, the signed written consent and completed questionnaires were returned in separate envelopes either by the patient at the next radiation appointment or by mail in a self-addressed, stamped return envelope. If the FCs identified by the patient did not send back the consent form and questionnaires, he/she was contacted once by phone by the RA and asked about their interested to participate in the study. A detailed description of the recruitment method is described in a separate paper [28].

To be eligible, both the FC and the cancer patient had to agree to participate in the study. Eligibility criteria for cancer patients were: newly diagnosed with cancer or a new recurrence; receiving radiation treatment; above 18 years of age and having a FC above 18 years of age at the time of recruitment. Both were able to read, write, and understand Norwegian; and both had secure internet access at home - a requirement for the other part of the study (not reported here) that investigated the effects of an Internet support system for cancer patients and FCs.

Instruments

The variables measured in this study are summarized in Table 1. Bothe the cancer patients and their FCs were asked to complete questionnaires on demographic characteristics and self-reported medical history information, and measures of symptoms, sleep disturbance, fatigue, depression, and self-efficacy. The cancer behavior inventory (CBI) was completed by the cancer patients only and caregiver reaction assessment (CRA) by FCs only. The patients' medical records were reviewed for disease and treatment information.

Set in Table 1 here

Variables measured

The demographic questionnaires asked patients and FCs for information on age, marital status (married or not married to cancer patient), living situation (living with the patient/FC or not), relation to the patient with cancer (spouse, family member or other), level of education (primary, secondary, college/university ≥ 4 years) and employment status (full/part time, sick leave or retired/unemployment).

Caregiver burden and experiences was measured *in FCs only* with the Caregiver Reaction Assessment (CRA) Scale [15,30]. The CRA is a 24-item instrument, assessing both positive and negative reactions to care giving, and asks caregivers to indicate their level of agreement to statements using a 5-point Likert-type scale, with the format: 1= strongly disagree, 2= disagree, 3= neither agree nor disagree, 4=agree, 5=strongly agree. The CRA measures five dimensions of the FCs situation. Lack of Family Support (5 items), assesses the FCs sense of other family members having left him or her to provide all of the patient's care. Impact on Health (4 items) refers to the FCs perception that his or her health has suffered as a result of the obligations of care-giving. The impact on Schedule (5 items) indicates the perceived effort and difficulty of obtaining health care needs and making care-related arrangements. Impact on Finances (3 items) measures economic costs and losses likely caused by caregiving. Caregiver Esteem (7 items) measures the perceived positive aspects of care giving. CRA total scores are generated by summing up the individual items. Four of the CRA-dimensions are constructed in such a way that higher numbers indicate high level of burden, while the self-esteem dimension is constructed in the opposite manner: a low score indicates negative reactions to or high burden of caring.

Fatigue was measured using the 18-item Lee Fatigue Scale (LFS) that consists of 18 items with two subscales to assess *fatigue* and *energy levels* [31-32]. A fatigue severity score is calculated as the mean items (ranging from 0-10) in the fatigue and energy subscales, with higher scores indicating higher levels of perceived fatigue and lower energy respectively.

Sleep disturbance was assessed with the 21–items General Sleep Disturbance Scale (GSDS) that evaluates various aspects of sleep disturbance [33-34]. Each item ranges from 0 (never) to 7 (every day). The total GSDS score is the sum of seven subscale scores (quality of sleep, quantity of sleep, sleep onset latency, midsleep awakenings, early awakenings, medications for sleep, excessive daytime sleepiness) with a total range from 0 (no disturbance) to 147 (extreme disturbance). Higher total and subscale scores indicate higher levels of sleep disturbance. Subscales scores of ≥ 3 and a total score of ≥ 43 indicate a significant level of sleep disturbance.

Depression was assessed using the Center for Epidemiologic Studies Depression Scale (CES-D) [35] with responses on 4-point Likert scales raging from 0 (rarely or none of the time) to 3 (most of the time). Higher scores indicated greater depression [36]. The CES-D is scored by summing individual items to a total score that can range from zero to 60. Higher scores indicate the presence of more depressive symptoms, weighted by frequency of occurrence during the previous week. Cut off score of 16 or higher for the 4 subscales indicates the need for referral to a clinical evaluation for major depression [36].

Social support was measured with the 20-item Medical Outcomes Study Social Support Survey (MOS-SS), including five subscales addressing emotional/informational instrumental, tangible and affectionate support and positive social interaction. Responses on 5-point Likert scales range from 6 (none of the time) to 4 (all the time). The sum of all items results in a total social support score [37]. Higher scores indicate more social support.

In FCs, self-efficacy was measured with the General Self-Efficacy Scale (GSE) [38] consisting of 10-items to predict coping with daily hassles as well as adaptation after experiencing all kinds of stressful life events. Responses are made on a 4-point scale. Total scores are computed by summing up the responses to all 10 items to yield the final composite score with a range from 10 to 40. The higher score indicates higher level of self-efficacy.

In cancer patients, self-efficacy was measured with the 33 items Cancer Behavior Inventory (CBI) [39]. The 33-item CBI consists of seven factors to measure cancer related to: (1) maintenance of activity and independence, (2) seeking and understanding medical information, (3) stress management, (4) coping with treatment-related side-effects, (5) accepting cancer/maintaining a positive attitude, (6) affective regulation, and (7) seeking support. Responses on 9-point Likert scales range from 1 (not at all confident) to 9 (totally confident). Higher scores indicate greater self-efficacy.

Symptom distress was measured with the Memorial symptom assessment scale (MSAS) [40]. Thirty-two items of MSAS list physical and psychological symptoms that occur in relation to cancer or its treatment. Patients were asked to indicate whether they had experienced the symptom during the previous week. If they had experienced the symptom, they were asked to rate its frequency, severity, and distress. Higher scores indicate greater symptom distress.

Statistical Analysis

Descriptive analyses are described as means, ranges and standard deviations. Categorical data are presented as counts and percentages. Associations between demographic variables, comorbidity, symptoms, sleep, fatigue, depression, social support, self-efficacy and caregiver burden total score were analyzed using a linear regression analysis. Two separate models were fitted – one for FCs and one for cancer patients. Baseline data were adjusted for gender, age, and marital status (married or not married to cancer patient). A p-value < .05 was considered to be statistically significant.

Results

Demographic characteristics for FCs and cancer patients are shown in Table 2. Slightly more than 50% of FCs and cancer patients in this study were female. The mean age for FC was 56 years and 57 years for the patients. The majority of FCs and cancer patients were married and lived together. While almost two thirds of FCs worked full or part time, only 15% of the cancer patients did. Almost all the FCs (95%) and 65% of the cancer patients reported at least one existing comorbidity. The majority of the FCs and cancer patients had a college degree. The most prevalent types of cancer were breast and prostate cancers.

Set in Table 2 here

Table 3a and 3b display the means and standard deviations for caregiver burden and the variables social support, depression, symptoms, fatigue, sleep disturbance and self-efficacy in FCs and patients.

Set in Table 3 here

The mean scores for each of the caregiver burden domains (CRA) indicate that FCs experienced between medium to high caregiver burden on some of the subscales. Care giving had the highest impact on FCs esteem, and medium impact on their health and daily schedule. The impact was less on family support and finance. No statistically significant gender differences were identified.

Measures of social support, including emotional/informational -, tangible- , affectionate support, and positive social interaction and the total score indicate that both FCs and cancer patients received a relatively high degree of social support. Cancer patients receive slightly more social support than their FCs. This difference is not statistically significant.

The mean total depression and subscale scores were under 36 of maximum 60 and the cutoff point of 16 (cancer patients: n=239 and FCs: n=251 scored under cut off score 16), indicating no need for treatment, for both cancer patients and their FCs. Depression was slightly higher in cancer patients than in FCs. There were large variations in depression scores in both groups, and differences in depression between patients and FCs was not statistically significant.

Both FCs (n=281) and cancer patients (n=281) suffered from low degree of depression with the lowest total score value of 18 and 20, respectively (data not shown in Table 3).

Patients reported higher fatigue and lower energy levels than their FCs. The difference in fatigue and energy level between patients and their FCs were statistically significant ($p<.05$). In both groups, fatigue was higher in females and energy levels were higher for males. In cancer patients only, female cancer patients had also significant higher fatigue scores ($p< .01$) and lower energy levels ($p= .05$) than male cancer patients (data not shown in Table 3).

Both FCs and cancer patients of both genders reported sleep disturbance higher than the cut- off point of 43, indicating substantial sleep disturbance in both groups. Sleep disturbance was higher in female FCs and cancer patients than in male participants; significantly for patients ($p < .01$) and not significant for FCs ($p= .07$), indicating that females in both groups suffer more from disturbed sleep. Sleep disturbance was higher in female cancer patients compared to female FCs.

General Self-Efficacy was similar between FCs and patients, and only marginally higher in male FCs. However, male FCs reported slightly higher self-efficacy than female FCs.

Self-efficacy for coping with cancer-related stress (CBI) was measured in cancer patients only. Results indicate a relatively high level of self-reported self-efficacy. As listed in Table 3, the highest baseline self-efficacy score (38.5) in cancer patients was computed for the item: seek and try to understand the medical information.

Symptom assessment (MSAS) results show a higher total score in patients, especially female than their FCs. A majority of cancer patients suffered from more than 5 symptoms as shown in Table 3.

Multivariate analyses

Multivariate analyses were adjusted for age and gender. Table 4 below displays the results. Higher scores of depression, fatigue and symptoms *in FCs* were significantly associated (p< .01) with higher caregiver burden. Sleep disturbance, energy, fatigue, self-efficacy and social support in FCs were not statistically significant predictors of caregiver burden.

The strongest predictors for caregiver burden among *patient-related* variables were sleep disturbance (p = .03), self-efficacy (p= .02) and social support (p=.04). The lower the self-efficacy and the more sleep disturbance patients experienced, the higher was FCs perceived caregiver burden. Inversely, higher levels of social support in patients were associated with lower levels of caregiver burden in FCs. Depression, fatigue, energy levels and symptoms in patients were not significantly associated with caregiver burden.

Set in Table 4 about here.

Discussion

Higher scores in depression and fatigue in FCs, when adjusting for age and gender, were significantly associated with higher caregiver burden, while sleep disturbance, energy fatigue, self-efficacy and social support in FCs was not. Symptoms in FCs had a significant association with caregiver burden while the symptoms in patients did not. Among patient-related variables, the strongest predictor of caregiver burden was self-efficacy followed by sleep disturbance and social support. Sleep disturbance and fatigue were gender related. Both female cancer patients and female FCs reported a higher degree of sleep disturbance and fatigue compared to male patients and FCs. Both FCs and patients received a high degree of social support, yet cancer patients received slightly more. Although cancer patients received more social support than their FCs, the impact of low social support in cancer patients on caregiver burden was significant.

The study results, showing that depression, fatigue and symptoms in FCs, and sleep disturbance, self-efficacy and social support in patients, are significant predictors of caregiver burden are interesting: Our study indicates that the patient and FCs characteristics contributing to caregiver burden are not necessarily the same. Rather, it seems that different patients and FCs variables play together. It is reasonable to believe that a patient who sleeps poorly and has low social support and self-efficacy may also keep his/her FC more up at night, rely more on the FC for social support, and needs more help from the FC to manage the different aspects of coping with the illness, which, in turn, adds to the FCs fatigue, depression and caregiver burden. That the symptoms and problems of both patients and FCs interact is also supported in other studies reporting that fatigue levels in patients significantly contribute to caregiver burden [41] and that sleep disturbance in patients is associated with depression in FCs [42-43, 30]. However, so far, there is only a beginning understanding about such inter-dependencies, e.g. how much of FCs experience of fatigue, depression and caregiver burden can be attributed to characteristics of the patient or to characteristics of the FC him/herself. For example, some FCs may be more prone to being depressed and fatigued than others, independent of the condition of the patient. On the other hand, depression and fatigue in FCs may also keep the patient worrying and in turn increase poor sleep, feelings of receiving little social support and help in managing the illness. Therefore, further studies should tease out the direct and indirect pathways by which patient and FCs variables interrelate and contribute to patients' and FCs symptoms/problems and caregiver burden. Also, our study included only a limited set of variables candidates to influence for caregiver burden while others variables may be equally important. For example, other studies have also identified levels of anxiety [44], marital satisfaction, role problems and distress [45] and care giver self-esteem [46] as predictors of caregiver burden.

Most studies so far, including ours, have focused on the *problems* of patients and FCs that add to caregiver burden. Little is known about the influence of positive characteristics, e.g. resilience, optimism or positive mood in patients and/or FCs that may act as a "buffer" against symptoms and problems. Our finding that the more self-efficacy the patient and FCs had the less was caregiver burden, indicates that self-efficacy can be such a buffer. More studies are needed to better understand how FCs and patients mutually influence each other in their illness and caregiver experiences, the characteristics of FCs and patients that put them at a particular risk for developing symptoms and problems, and which characteristics that help prevent this.

Age was not associated with caregiver burden in our study. However, most FCs and patients reported at least one comorbidity, and the likelihood of comorbidities generally increases with age. Thus, health issues other than the patients' cancer diagnosis could also affect FCs fatigue, depression and caregiver burden. Clinical assessments should therefore include screening for and helping patients and FCs in making sure that comorbidities are under control.

Our finding that women report more symptoms and problems than men, independent of being a FC or a patient, is consistent with other studies. For example, Northouse and colleagues, in their study of couples' adjustment to colon cancer [45], reported that women reported more distress, role problems and less marital satisfaction regardless of whether they were a patient or spouse. In a study on FCs only, Stenberg et al [46] reported that female caregivers reported significantly higher scores on impact of care giving on health, finances, greater lack of family support and lower caregiver self-esteem than male FCs. In our study, male FCs and patients reported less fatigue and less sleep disturbance that women, variables that were significantly associated with caregiver burden. These differences are important from a clinical perspective as they indicate that female patients and FCs may be in need for more professional support.

That patients and FCs reported on average relatively low fatigue and depression under the cut-off point for a clinical depression diagnosis may be due to the early stage of treatment in which the study was conducted. This should not mislead readers to believe that low scores at an early stage does not put patients and FCS at risk for more severe symptoms during the course of the illness over time, as found in other studies [45-46]. We found strong associations between caregiver burden and depression and fatigue in FCs, and sleep disturbance, self-efficacy, memorial symptoms and social support respectively even at this early stage. Early screening of symptoms could therefore identify FCs and patients at particular risk.

Although patients reported more social support than FCs, the impact of low social support in patients on caregiver burden was still statistically significant. Several factors may have influenced these findings. When diagnosed with cancer, it is usually the patient who gets more support and attention from others than the FC who's role in giving care is taken more "for granted". The demands of giving care reduce the possibility to maintain normal social interactions for the FC [46], and thus reduce access to social support. However, when also the patient receives low social support from elsewhere, the FC becomes the primary source of social support for the patient, adding to the demands of the FCs and caregiver burden. Assessing the patient's and FCs social network and encouraging them to reach out to other sources of support, if available, may thus help reduce one of factors that increase caregiver burden.

Implication for clinical practice.

The results from this study have important implications for clinical nursing practice. They can heighten the awareness of oncology nurses and other health professionals of the difficulties FCs face in their role as caregivers and the need to include FCs as a natural part into the care of the patient. Our and other studies [42-43,45] clearly indicate that there is a close inter-relationship between patients and FCs symptoms and problems that impact the health of both the patients and their FCs, and how well patients manage and live with a cancer diagnoses. Recognizing and assessing the problems and symptoms of patients as well as FCs at the time of diagnosis and early treatment is essential to prevent symptom development and deterioration. FCs are usually the most important source of support for cancer patient. While more evidence is needed to support this, assisting both the patients and FCs may positively affect the outcome of the cancer diagnosis.

Nurses should also be aware of the increased risk for female cancer patients and FCs to develop problems and symptoms, and that women may have special needs for support. Finally, it is important for nurses to recognize that multiple factors, such as demographic characteristics, medical factors and personal attributes influence how well cancer patients and FCs adapt to the illness, and that an assessment and interventions for symptoms and problems in patients and FCs at an early stage may influence how well they adjust to the illness over time.

Strengths and Limitations

Our study addressed the problems and symptoms of FCs that are often overlooked in clinical practice and research. A strength of the study is its relatively large sample size and rigorous data collection with validated measures. We had enough statistical power to detect statistically significant differences and our results should be relatively robust. However, there are also limitations: Data were collected at one setting only, the radiology department at one university hospital in Norway. Participants in our study had higher education levels than the average level of education in cancer patients. Because the purpose of another part of the study was test the effects of Internet support for patients and FCs, study participants had to have Internet access, the inclusion criteria may have played a role for the higher than usual education as well as results on study variables.

The data reported here are cross-sectional and are, for most of the patients, collected in an early phase of treatment close to receiving a cancer diagnosis. Thus, findings are not generalizable to patients with advanced or metastatic disease or illness stages beyond the early phase of treatment. The study did include cancer patients who received both palliative (10%) and curative treatment (90%) at the time of initiation of their radiation treatment. The time period for which palliative care patients had been receiving treatment was not collected in this study and the sample size was too small to conduct subgroup analyses for patients receiving palliative radiotherapy. However, the small percentage of patients in a palliative phase and findings from other studies that symptom burden is more linked to the treatment and less whether the patients are in a palliative or curative phase [42], suggests that a potential influence, on study results of palliative care may be small. However, more research is needed to investigate how the stage of illness and length of time in cancer treatment affect patients and FCs and care giver burden.

Conclusion

Depression, symptoms, and fatigue in FCs, and sleep disturbance, low self-efficacy and low social support in cancer patients had significant impact on caregiver burden. This study also found a significant influence of gender on caregiver burden. Female participants among cancer patients and FCs reported more problems compared to the male participants.

References

1. Torre LA, Bray F, Siegel RL, et al. Global cancer statistics, 2012. CA Cancer J Clin. 2015;65(2):87-108.
2. Cancer in Norway 2013, Cancer Registry of Norway : Web Site. http://www.kreftregisteret.no/Global/Cancer%20in%20Norway/2013/CIN_2013.pdf. Accessed May 26, 2016.
3. Stenberg U, Cvancarova M, Ekstedt M, Olsson M, Ruland C. Family caregivers of cancer patients: perceived burden and symptoms during the early phases of cancer treatment. Soc Work Health Care. 2014;53(3):289-309.
4. Given BA, Given CW, Kozachik S. Family support in advanced cancer. CA Cancer J Clin2001;51:213-231
5. Kim Y, Baker F, Spiller RL, Wellisch DK. Psychological adjustment of cancer caregivers with multiple roles. Psychooncology. 2006;15:795-804.
6. Kim Y, Schulz R. Family caregivers' strain: comparative analysis of cancer caregiving wih dementia, diabetes, and frail elderly caregiving. J Aging Health. 2008;20(5):483-503.
7. Nijboer C, Tempelaar R, Sanderman R, Triemstra M, Spruijt RJ, van den Bos GA. Cancer and caregiving: the impact on the caregiver's health. Psychooncology. 1998;7:3-13.
8. Hagedoorn M, Buunk BP, Kuijer RG, Wobbes T, Sanderman R: Couples dealing with cancer: role and gender differences regarding psychological distress and quality of life. Psychooncology. 2000;9:232-242.
9. Bultz BD, Speca M, Brasher PM, Geggie PH, Page SA: A randomized controlled trial of a brief psychoeducational support group for partners of early stage breast cancer patients. Psychooncology. 2000;9:303-313.

10. Carlson LE, Ottenbreit N, St PM, Bultz BD: Partner understanding of the breast and prostate cancer experience. Cancer Nursing. 2001;24:231-239.

11. Morse SR, Fife B: Coping with a partner's cancer: adjustment at four stages of the illness trajectory. Onc Nurs. 1998; 25:751-760.

12. Zabora JR, Smith ED, Baker F, Wingard JR, Curbow B: The family: the other side of bone marrow transplantation. J Psychooncology. 1992;10:35-46.

13. McCausland J, Pakenham KL. Investigation of the benefits of HIV/AIDS caregiving and relations among caregiving adjustment, benefit finding, and stress and coping variables. AIDS Care. 2003;15:853-869.

14. Folkman S, Chesney MA, Cooke M, Boccellari A, Collette I. Caregiver burden in HIV-positive and HIV-negative partners of men with AIDS. J Consult Psycho. 1994;62:746-756.

15. Kim Y, Schultz R, Carver CS, Benefit-finding in the cancer caregiving experiences. Psychosom Med. 2007;69:283-291.

16. Given CW, Given BA, Stommel M, Collins C, King S, Franklin S. The caregiver reaction assessment (CRA) for caregivers to persons with chronic physical and mental impairments. Res Nurs Health. 1992;15:271-283.

17. Folkman S, Chesney MA, Christopher-Richards A. Stress and coping in caregiving partners of men with AIDS. Psychiatr Clin North Am. 1994;17:35-53.

18. Ferrell BR, Dow KH, Grant M. Measurement of the quality of life in cancer survivors. Qual Life Res. 1995;4:523-531.

19. Ferrell BR, Grant M, Padilla G, Vemuri S. The experience of pain and perceptions of quality of life: validation of a conceptual model. Hospice J. 1991;7:9-24.

20. Haley WE, LaMonde LA, Han B, Burton AM, Schonwetter R. Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model. J Palliat Med. 2003;6:215-224.

21. Portenoy RK, Thaler HT, Kornblith AB, Lepore JM, Friedlander-Klar H, Coyle N, Smart-Curley T, Kemeny N, Norton L, Hoskins W: Symptom prevalence, characteristics and distress in a cancer population. Quality of Life Research. 1994;3:183-189.

22. Holmes S: Preliminary investigations of symptom distress in two cancer patient populations: evaluation of a measurement instrument. Journal of Advanced Nursing. 1991;16:439-446.

23. Derogatis LR, Morrow GR, Fetting J, et al. The prevalence of pschyiatric dirorders among cancer patients. JAMA. 1983;249:751-757.
24. Parle M, Jones B, Maguire P. Maladaptive coping and affective disorders among cancer patients. Psychol Med. 1996;26:735-744.
25. Harrison J, Magquire P. predictors of psychiatric morbidity in cancer patients. Br Psychiatry. 1994;165:593-598.
26. Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. Washington, DC: National Acedemies Press; 2001.
27. Epstein R, Fiscella K, Lesser CS, Stange K. Why the nation needs a policy push on patient-centered health care. Health Aff. 2010;29:1489-1495.
28. Sygna K, Johansen S, Ruland CM. Recruitment challenges in clinical research including cancer patients and their caregivers- A randomized controlled trial study and lessons learned. Trials. 2015;17:133.
29. Charlson ME, Pompei P, Ales KL, et al. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis. 1987;40(5):373-383.
30. Grov EK, Fossa SD, Tonnessen A, Dahl AA. The caregiver reaction assessment: pscychometrics, and temporal stability in primary caregivers of Norwegian cancer patients in late palliative phase. Psychooncology. 2006;15(6):517-527.
31. Lerdal A, Kottorp A, Gay CL, Lee KA. Lee Fatigue and Energy Scales: exploring aspects of validity in a sample of women with HIV using an application of a Rasch modell. Psychiatr Res. 2013;205(3):241-246.
32. Lee KA, Hicks G, Nino-Murcia G. Validity and reliability of a scale to assess fatigue. Psychiatr Res. 1991;36(3):291-298.
33. Lee KA. Slef-reported sleep disturbances in employed women. Sleep. 1992;15(6):493-498.
34. Carney S, Koetters T, Cho M, et al. Differences in sleep disturbance parameters between oncology outpatients and their family caregivers. Journal of Clin Oncol. 2011;29(8):1001-1006.
35. Radloff LS, Teri L. Use of the Center for Epidemiological Studies-Depression Scale with older adults. WCLI. 1986;5(1):119-136.
36. Carpenter JS, Andrykowski MA, Wilson J, et al. Psychometrics for two short forms of the Center for Epidemiologic Studies–Depression Scale. *Issues in Mental Health Nursing. 1998;19*(5):481–494.
37. Sherbourne CD, Stewart Al. The MOS social support survey. Soc Sci Med. 1991;32(6):705-714.

38. Schwarzer R, Jerusalem M. Generalized Self-Efficacy scale. In: Weinman J, Wright S, Johnston M. *Measures in health psychology: A user's portfolio. Causal and control beliefs*; Windsor UK, NFER-NELSON 1995:35-37.
39. Merluzzi TV, Nairn RC, Hegde K, Martinez Sanchez MA, Dunn L. Self-efficacy and coping with cancer: Revision of the Cancer Behavior Inventory (Version 2.0). Psycho-Oncology. 2001; 10:206–217.
40. Portenoy RK, Thaler HT, Kornblith AB, Lepore JM, Friedlander-Klar H, Kiyasu E, Sobel K, Coyle N, Kemeny N, Norton L. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer. 1994;30A(9):1326–36.
41. Passik SD, Kirsh KL. A pilot examination of the impact of cancer patients' fatigue on their spousal caregivers. Palliative and Supportive Care. 2005;3:273-279.
42. Valeberg BT, Grov EK. Symptoms in the cancer patient – of importance for their caregivers' quality of life and mental health? Eur J Oncol Nursing. 2013;17:46-51.
43. Cora A, Partinico M, Munafó M, et al. Health risk factors in caregivers of terminal cancer patients. Cancer Nursing. 2012;35:38-47.
44. Walsh D, Donnelly S, Rybicki L. The symptoms of advanced cancer; relationship to age, gender and performance status I 1,000 patients. Supportive Care in Cancer.2000;8;175-179.
45. Northouse LL, Mood D, Templin T, et al. Couples' patterns of adjustment to colon cancer. Soc Sci Med. 2000;50:(2):271-84.
46. Stenberg U, Cvancarova m, Olsson M, et al. Family caregivers of cancer patients: perceived burden and symptoms during the early phases of cancer treatment. Soc Work Health Care. 2014;53(3):289-309.

Table legend

Table 1

Data Collected from Cancer Patients, Their Family Caregivers and Instruments.

Table 2

Demographic Characteristics – Family Caregivers and Patients

Table 3

Caregiver and Patient Baseline Mean Severity Scores on Care Giver Reaction Assessment (CRA), Medical Outcomes Study Support Survey (MOS), Epidemiological Studies Depression Scale (CES-D), Lee Fatigue Scale (LFS), The General Sleep Disturbance Scale (GSDS), The General Self-Efficacy Scale (GSE 10), Cancer Behavior inventory (CBI), and Memorial Symptom Assessment Scale (MSAS)

Table 4-a

Predictors in Family Caregivers for caregiver Burden. Multiple Linear Regression Adjusted for Age and Gender

Table 4-b

Predictors in Cancer Patients of Caregiver Burden. Multiple Linear Regression Adjusted for Age and Gender

Table 1

Data Collected from Cancer Patients, Their Family Caregivers and Instruments.

Concepts measured	**Instruments**	**Patient-caregiver**	
Demographics	Study specific	**X**	**X**
Cormorbidty	Charlson Comorbidity Index	**X**	**X**
Caregiver burden	CRA, Care Giver Reaction Assessment	**X**	
Fatigue	LFS, Lee Fatigue Scale	**X**	**X**
Sleep Disturbance	GSDS, General Sleep Disturbance Scale	**X**	**X**
Depression	CES-D, Center for Epidemiologic Studies Depression Scale	**X**	**X**
Social Support	MOS-SS, Medical Outcomes Study Social Support Survey	**X**	**X**
Self-efficacy - caregivers	GSE, General Self-Efficacy Scale	**X**	**X**
Self-efficacy - Cancer patients	CBI, Cancer Behavior Inventory	**X**	
Symptoms (general)	MSAS, Memorial Symptom Assessment	**X**	**X**

	Scale	

Abbreviations: FCs, Family caregivers; CRA, Care Giver Reaction Assessment; MOS, Medical Outcomes Study Support Survey; CES-D, Epidemiological Studies Depression Scale; LFS, Lee Fatigue Scale; GSDS, The General Sleep Disturbance Scale; GSE, The General Self-Efficacy Scale; CBI, Cancer Behavior inventory; MSAS, Memorial Symptom Assessment Scale

Table 2
Demographic Characteristics – Family Caregivers and Patients

Characteristics		**FCs**	**Patients**
Total sample	Range 18-86	281	281
Gender	Male	132	119
	Female	149	162
Median age (years)		56	57
	≤50år	96	91
	>50år	185	190
Marital status	Married to the patient/partner	251	251
	Other	30	30
Living together with the patients	Yes	234	234
	No	44	44
Relationship to the patient	Spouse/partner	227	
	Family member	45	
	Other	9	

Education level			
	College/university ≥ 4 Years	147	172
	Secondary (1-3 years)	113	93
	Primary school	18	16
Employment status	Full time/part time work	180	48
	Pension/disability pension	69	145
	On sick leave	32	88
Patient's cancer diagnosis	Breast cancer		118
	Prostate cancer		63
	Head & neck and skin cancer		42
	Myelomatose and Lymphoma		31
	Other		27
Comorbidity	Existing comorbidity	274	183
	Neck and back pain	91	79
	Heart disease	69	22
	Arthrosis	49	39
	Head pain	37	30
	FCs/patients with one disease	80	1
	FCs/patients with two diseases	47	3
	FCs/patients with three disease	29	8
	FCs/patients with four diseases	15	22
	FCs/patients with five or more diseases	7	241
	FCs/patients with no comorbidity	93	3

Abreviations: FCs, Family caregivers

Table 3

Caregiver and Patient Baseline Mean Severity Scores on Care Giver Reaction Assessment (CRA), Medical Outcomes Study Support Survey (MOS), Epidemiological Studies Depression Scale (CES-D), Lee Fatigue Scale (LFS), The General Sleep Disturbance Scale (GSDS), The General Self-Efficacy Scale (GSE 10), Cancer Behavior inventory (CBI), and Memorial Symptom Assessment Scale (MSAS)

Variables		**Caregiver-** **Mean**	**SD**	**Patient-** **Mean**	**SD**	**p-value** (n.s= not significant)
Care giver burden (CRA)	Lack of family support	1.8	0.6			
	Male	1.7	0.6			
	Female	1.9	0.7			
	Impact on Health	2.4	0.5			
	Male	2.3	0.5			
	Female	2.4	0.5			
	Impact on daily schedule	2.4	0.8			
	Male	2.5	0.8			
	Female	2.3	0.8			
	Caregivers Esteem	4.1	0.6			
	Male	4.2	0.6			
	Female	4.1	0.6			
	Impact on finance	1.9	0.8			
	Male	1.7	0.8			
	Female	2.0	0.8			
Support (MOS)	Tangible support	71.5	26.5	79.0	20.6	.03
	Affectionate support	84.1	19.9	85.8	19.6	n.s
	Positive Social interaction	82.9	19.2	83.4	17.6	n.s
	Emotional/informational support	75.5	23.1	75.7	20.2	n.s
	Social support total score	75.8	20.6	79.2	18.0	n.s.
	Male	75.7	21.2	78.3	18.9	n.s
	Female	76.0	20.0	79.9	17.3	n.s
Depression (CES-D)	Depressed effect	10.2	3.7	10.9	3.8	n.s.

high ≥ 16	Positive effect	9.8	4.7	8.9	4.5	n.s
	Somatic and retarded activity	9.6	3.5	11.4	3.8	.04
	Interpersonal	3.9	1.2	4.0	1.1	n.s.
	Total score	33.6	6.8	35.2	6.6	n.s
	Male	32.4	6.7	35.9	6.8	.04
	Female	34.6	6.8	34.6	6.2	n.s.
Fatigue (LFS)						
Fatigue score	Total	3.0	2.0	4.1	2.0	.03
	Male	2.8	2.1	3.6	2.2	n.s
	Female	3.1	2.1	4.4	2.1	.02
Energy level	Total	6.1	1.9	4.9	2.0	.03
	Male	6.2	1.9	5.3	2.1	.04
	Female	5.9	1.9	4.8	1.8	.03
Sleep Disturbance (GSDS)						
Total score	Total score	47.1	20.8	58.3	22.1	.01
	Male	44.0	21.6	54.8	22.1	.01
High when ≥ 43	Female	49.8	21.5	59.6	22.2	.01
	Medication for sleep	0.5	0.5	0.7	0.9	n.s
High if;	Quality of sleep	3.1	0.4	3.6	2.0	.03
Subscales scores ≥ 3	Sleep onset latency	1.6	0.6	2.6	2.4	.03
	Quantity of sleep	4.9	0.8	2.4	2.4	.01
	Mid sleep wakes	3.6	0.6	5.0	2.2	.01
	Early awakening	2.1	0.5	2.5	2.3	n.s.
	Excessive day time sleepiness	2.3	0.5	3.0	1.4	.04
Self-efficacy (GSE 10)						
	Total score	30.2	5.7	29.2	5.9	n.s.
	Male	31.1	5.3	29.2	5.9	n.s.
	Female	29.3	5.9	29.2	5.8	n.s,
Cancer Behviour Inventory (CBI)						

Maintenance of activity and independence (5 items)			33.9	8.4	
Seeking and understanding medical information (5 items)			38.5	7.0	
Stress management (5 items)			35.0	7.8	
Coping with treatment-related side effects (5 items)			32.1	9.6	
Accepting cancer and maintaining a positive attitude (5 items)			35.1	8.6	
Affective regulation (5 items)			32.3	8.2	
Seeking support (3 items)			20.6	5.5	
Total score			227.5	44.5	

Memorial Symptom Assessment Scale (MSAS)

Mean; 1=slight and 4 = very severe
Frequency; 1=rarely and 4=almost constantly

Total score	1.35	1.46	2.55	1.93	.03
Male	1.21	1.38	2.28	1.87	.01
Female	1.46	1.52	2.79	1.96	.01
Caregivers/Patients suffering from < 5					
Male	45		22		
Female	48		15		
Caregivers/Patients suffering from ≥ 5					
Male	82		108		
Female	96		133		

Abbreviations: CRA, Care Giver Reaction Assessment; MOS, Medical Outcomes Study Support Survey; CES-D, Epidemiological Studies Depression Scale; LFS, Lee Fatigue Scale; GSDS, The General Sleep Disturbance Scale; GSE, The General Self-Efficacy Scale; CBI, Cancer Behavior inventory; MSAS, Memorial Symptom Assessment Scale

Table 4-a

Predictors in Family Caregivers for Caregiver Burden. Multiple Linear Regression Adjusted for Age and Gender

Variable	B	95% CI	p-value
Depression	0.303	0.118; 0.488	**<.01**
Sleep disturbance	0.037	-0.040; 0.113	.35
Lee fatigue	1.968	1.154; 2.781	**<.01**
Energy fatigue	0.494	-0.274; 1.262	.21
Self-efficacy	-0.186	-0.417; 0.045	.11
Social support	0.028	-0.036; 0.092	.40
Memorial Symptom Assessment Scale -for caregivers	0.905	0.242; 1.569	**<.01**
Memorial Symptom Assessment Scale -for patients	0.265	-0.605; 1.135	.55

Table 4-b
Predictors in Cancer Patients of Caregiver Burden. Multiple Linear Regression Adjusted for Age and Gender

Variable	B	95% CI	p-value
Depression	-0.134	-0.380; 0.112	.28
Sleep disturbance	0.062	0.005; 0.119	**.03**
Lee fatigue	0.065	-0.780; 0.911	.88
Energy fatigue	-0.782	-1.605; 0.041	.06
Self-efficacy	-0.047	-0.086; -0.009	**.02**
Social support	-0.063	-0.123; -0.003	**.04**
Memorial Symptom Assessment Scale -for patients	0.676	-0.201; -1.554	.13