



Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression

Nanna Friðriksdóttir, Þórunn Sævarsdóttir, Svandís Íris Halfdánardóttir, Arndís Jónsdóttir, Hrefna Magnúsdóttir, Kristín Lára Ólafsdóttir, Guðbjörg Guðmundsdóttir & Sigríður Gunnarsdóttir

To cite this article: Nanna Friðriksdóttir, Þórunn Sævarsdóttir, Svandís Íris Halfdánardóttir, Arndís Jónsdóttir, Hrefna Magnúsdóttir, Kristín Lára Ólafsdóttir, Guðbjörg Guðmundsdóttir & Sigríður Gunnarsdóttir (2011) Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression, Acta Oncologica, 50:2, 252-258, DOI: [10.3109/0284186X.2010.529821](https://doi.org/10.3109/0284186X.2010.529821)

To link to this article: <https://doi.org/10.3109/0284186X.2010.529821>



Published online: 13 Jan 2011.



Submit your article to this journal [↗](#)



Article views: 7861



View related articles [↗](#)



Citing articles: 32 View citing articles [↗](#)

ORIGINAL ARTICLE

Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression

NANNA FRIÐRIKSDÓTTIR^{1,2}, ÞÓRUNN SÆVARSDÓTTIR¹, SVANDÍS ÍRIS HALFDÁNARDÓTTIR¹, ARNDÍS JÓNSDÓTTIR¹, HREFNA MAGNÚSDÓTTIR¹, KRISTÍN LÁRA ÓLAFSDÓTTIR¹, GUÐBJÖRG GUÐMUNDSDÓTTIR¹ & SIGRÍÐUR GUNNARSDÓTTIR^{1,2}

¹*Landspítali – The National University Hospital, Reykjavík, Iceland and* ²*University of Iceland, Faculty of Nursing, Reykjavík, Iceland*

Abstract

Background. Family members of cancer patients have multiple needs, many of which are not adequately met. Unmet needs may affect psychological distress and quality of life (QOL). The purpose of this study was to assess needs and unmet needs, QOL, symptoms of anxiety and depression, and the relationship between those variables in a large sample of family members of cancer patients in different phases of illness. **Material and methods.** Of 332 family members invited to participate, 330 accepted and 223 (67%) completed a cross-sectional, descriptive study. Data was collected with the Family Inventory of Needs (FIN), Quality of Life Scale (QOLS) and the Hospital Anxiety and Depression Scale (HADS). **Results.** Of 20 needs assessed the mean (SD) number of important needs and unmet needs was 16.4 ± 4.3 and 6.2 ± 5.6 , respectively. Twelve important needs were unmet in 40–56% of the sample. The mean number of unmet needs was significantly higher among women than men, other relatives than spouses, younger family members, those currently working and those of patients with metastatic cancer. QOL was similar to what has been reported for healthy populations and cancer caregivers in advanced stages. The prevalence of symptoms of anxiety and depression was high (20–40%). Anxiety scores were higher among women than men and both anxiety and depression scores were highest during years 1–5 compared to the first year and more than five years post diagnosis. There was a positive relationship between number of important needs and QOL, and between needs met and QOL. Additionally, there was a significant relationship between anxiety and unmet needs. Finally, there was a significant relationship between QOL and symptoms of anxiety and depression. **Conclusion.** The results support the importance of screening needs and psychological distress among family members of cancer patients in all phases of illness.

It is well known that family members of cancer patients are affected by the illness throughout its trajectory [1–3]. Psychological distress, the most studied aspect of quality of life (QOL) in caregivers of cancer patients [3], is highly prevalent, particularly in advanced stages of illness [2–7], and research indicates higher levels of anxiety and depression than in the general population or even in cancer patients [2,4,5,7]. A recent meta-analysis supports that gender may be a more important determinant of distress than role (patient vs. caregiver) [8]. Although not consistent, more caregiver distress has been associated with being a woman, younger age, being

a spouse, and employed [2,3]. Furthermore, cancer caregivers distress has been associated with higher than average number of supportive care needs [4], lack of support [2,3], poorer QOL [3,15] and caregiver burden [2,3].

Family members' needs in relation to patient comfort and care, information, support and communication are all important [4,9,11], however, some studies show that many needs are not adequately met by health professionals [4,6,11,13,14]. Unmet needs have been found to be associated with impaired work performance [12], anxiety [6], more caregiver burden [16] and less caregiver satisfaction

[14]. Unmet caregiver needs have also been correlated with patients own unmet needs and emotional functioning [6] and with poorer quality of patient care provided by the family [12]. Furthermore, unmet caregiver needs have been found more common in conventional hospital units than in specialized palliative care settings [11,12]. Most studies on the relationship between unmet needs and caregiver outcomes have been conducted in later stages of illness with small samples. One recent study, however, reported on the relationship of unmet needs and QOL outcomes at three different phases, two months, two, and five years post diagnosis, among cancer caregivers [13]. Caregivers whose psychosocial needs were not met reported poorer mental health at all time points and the authors concluded that unmet psychosocial needs were a consistent predictor of poor mental health, beyond the effects of a host of demographic variables [13].

Given the role that family members are expected to play in the supportive care of patients, health care providers emphasize that the unit of care includes both the patient and the family [1–3,9,10]. Furthermore, it is argued that for family supportive interventions to be effective they must be based on needs assessments to guide care planning [9,10]. At Landspítali University Hospital (LSH) in Iceland an emphasis has been placed on family support both in cancer and palliative care settings. Access to psychosocial services is provided, family meetings are regularly offered, and a family nursing model has been integrated into daily care. However, regular and specific needs assessments as well as distress screening and specific family interventions have not been provided.

In order to improve care it is important to understand needs and the relationship between unmet needs and variables such as psychological distress and QOL. Most studies on this issue have been conducted in advanced stages of illness and no studies in Iceland have addressed this issue. The purpose of this study was to assess needs and unmet needs, QOL, symptoms of anxiety and depression, and the relationship between those variables in a large sample of family members of cancer patients receiving care in different phases of illness at LSH.

Material and methods

Design and setting

The study design was cross-sectional, descriptive and correlational. Data was collected at six units serving cancer patients at LSH. These included a medical oncology and haematology outpatient clinic, a radiation outpatient clinic, a oncology inpatient

unit, a haematology inpatient unit, a palliative care inpatient unit, and palliative home care.

Sample and procedure

During a six month period, cancer patients admitted for three days or longer to an inpatient unit, or scheduled for visit number three or more at an outpatient clinic or at home, were invited to participate. Patients were asked to identify a close and supportive caregiver or family member ≥ 18 years to participate. Participants were consented via phone to receive and return a questionnaire by mail. A one-time reminder telephone call was made two weeks later.

Instruments

Family Inventory of Needs (FIN). Family care needs, and the extent to which these were met were measured with the Icelandic validated version of FIN [11]. The instrument [17] is a standardized 20-item tool, consisting of two subscales assessing family needs as they relate to the present situation. The first subscale measures the importance of 20 care needs. In the original version, the response options range from 0 (not at all important) to 10 (very important). In the version used in this study, the response options range from 1 (not important) to 5 (very important). On the second subscale, the respondents are asked to indicate whether those needs rated as being important (rated 2 or more) have been met, partly met or not met by health care professionals. In this study Cronbach's alpha for the needs scale was 0.92 and the needs met scale 0.94.

Quality of Life Scale (QOLS). Quality of life was measured with the Icelandic validated version of the QOLS [18]. It contains 16 items scored on a 1–7 point satisfaction scale and measures five conceptual QOL domains: material and physical well-being, relationships with other people, social, community and civic activities, personal development and fulfilment, recreation and independence. The mean score of the scale items can range from 1–7 where higher scores indicate better QOL. Aggregated average total mean scores can range from 16–112 so that a higher score indicates better QOL. The average total score for healthy populations is about 90 [19]. The QOLS was originally developed from research on a healthy population, it has been validated and used in several international studies with diverse patients groups with chronic illnesses [19] and among cancer patient caregivers and norms in Norway [20]. In the present study, both the total mean score and the aggregated average total mean scores are presented, but only the

aggregated average mean score is used for statistical analysis. Both scores have been reported in previous research [18–20]. In this study Cronbach's alpha for the total QOL scale was 0.90.

Hospital Anxiety and Depression Scale (HADS). Symptoms of anxiety and depression were evaluated with the Icelandic validated version of HADS [21]. It consists of two subscales, each with seven items rated on a four-point Likert-scale indicating either symptoms of anxiety or depression during the past week. Possible range of scores is 0–21 for each scale. A score of 0 to 7 for either scale is regarded as being in the normal range (no symptoms), a score of 8 to 10 is suggestive of the presence of a mood disorder (possible symptoms), and a score of 11 or higher indicates probable presence of a mood disorder (symptoms) of the respective state. In this study Cronbach's alpha for the anxiety scale was 0.84 and 0.68 for the depression scale.

Demographics and background

Information was collected on gender, age, residency, relation to the patient, employment status and hours spent on daily direct caregiving. In addition information was collected on the patient's diagnosis, time since diagnosis, medical treatment, use of home care services and current care setting.

Statistical methods

Data were analyzed with the SPSS software for Windows (SPSS inc. Chicago, IL, USA). Descriptive and inferential statistics were used. Descriptive statistics were computed to describe the sample including means, standard deviations (SD) and percentages. For statistical comparison, correlations, independent sample t-tests, and ANOVAs with LSD correction for multiple comparisons were used. Statistical significance was set at $p < 0.05$.

Ethical approval

The study was approved by the bioethics committee of LSH and the Icelandic Data Protection Authority. This study was carried out in accordance with the Declaration of Helsinki of the World Medical Association (WMA; 2008).

Results

Sample description

The response rate was 67%, of 332 family members who were invited, 330 agreed to participate and 223

completed the study. The most common reasons for dropout were patient's death or deterioration. The majority of participants were women (62%), the patient's spouse (64%) and the mean (SD) age was 56 ± 13.6 years (range 18–82) (Table I). The majority were currently working (66%), and younger family members were more likely to be working than older ones ($p < 0.01$). The average (SD) time spent on daily direct caregiving was 3.5 ± 5.4 hours, with a range of 0–24. Family members in the palliative care setting spent more hours (1.6 ± 0.8) on daily patient care than family members in other settings (0.9 ± 0.8) ($p < 0.01$).

Half the patients (54%) had been diagnosed less than a year ago and nearly equal numbers had a localized (43%) or a metastatic cancer (44%). Approximately half (48%) were receiving care from outpatient units and the majority (63%) were not receiving home care.

Table I. Sample description (N = 223). Family member's characteristics and patient medical information.

	n (%)
Family member's gender	
Female	139 (62)
Male	84 (38)
Relation to patient	
Spouse	140 (64)
Others ¹	80 (36)
Family members age	
≤ 55 years	111 (51)
> 55 years	108 (49)
Family members currently working	
Yes	143 (66)
Working full-time	107 (73)
Working part-time	39 (27)
Family residency	
Capital area	168 (76)
Other	52 (24)
Time from patients diagnosis	
< 1 year	119 (54)
1–5 years	68 (32)
> 5 years	31 (14)
Stage of patients cancer	
Metastatic	91 (44)
Localized	90 (43)
Unknown	28 (13)
Care site at time of study	
Medical onc/hem outpatient	60 (27)
Radiation outpatient	46 (21)
Medical oncology inpatient	37 (17)
Palliative home care	33 (15)
Medical haematology inpatient	28 (13)
Palliative care inpatient	19 (8)
Receiving home care	
No	131 (63)
Home aid	34 (16)
Specialized palliative home care	49 (23)
Community home nursing	17 (8)

¹Adult children (26%), parent (4%), sibling (2%).

Important family care needs and unmet needs

The majority of the 20 needs assessed with FIN were considered to be important. The mean importance score for the 20 needs ranged from 3.8 to 4.9 (Table II). Twelve needs were considered important by $\geq 90\%$ of the sample. The two most common important needs reported by all family members (100%) related to patient care. The least common important need was reported by 57% of the sample and related to the family member's own well-being. The mean (SD) number of important needs scored either 4 (important) or 5 (very important) was 16.6 ± 4.3 (range 0–20).

The mean (SD) number of important needs that were met by health professionals was 9.9 ± 6.1 (range 0–20). The two most common important needs were also the two needs that were most often met in 73% and 80% of the sample, respectively. The mean (SD) number of unmet but important needs was 6.32 ± 5.65 (range 0–20). Twelve important needs were unmet in 40–56% of the sample. The two most common unmet needs were reported by 56% and 51% of the sample, respectively (Table II).

The mean number of important needs was significantly related to gender and age. Women had a higher mean number of important needs (17.3 ± 3.7) than men (15.6 ± 4.9) ($p = 0.02$) and younger family members (<55 years) had a higher (17.1 ± 3.7) mean number of needs than older ones (15.8 ± 4.9) ($p = 0.05$).

The mean number of unmet needs differed significantly by gender, relation to the patient, age, working status, and cancer stage. The mean number of unmet needs was higher among women (7.2 ± 5.5) than men (5.1 ± 5.7) ($p = 0.02$), among non-spouses than spouses (8.3 ± 5.5 vs. 5.1 ± 5.4) ($p < 0.01$), among younger (7.3 ± 5.7) than older ones (4.7 ± 5.1) ($p < 0.01$), among those currently working (6.9 ± 5.7) than those not working (4.6 ± 5.2) ($p = 0.02$) and among family members of patients with metastatic cancer (7.5 ± 5.6) than those of patients with localized cancer (4.9 ± 5.1) ($p < 0.01$).

Quality of life

The aggregated average total mean (SD) QOL score was 84.88 ± 14.72 , ranging from 16–112. The mean (SD) total QOL score was 5.47 ± 0.75 , ranging from 4.5 to 6.5. The mean total QOL scores for individual scale items are shown in Table III. No difference was found for background variables except that family members in the palliative care setting had a higher aggregated average total mean QOL score (88.47 ± 11.6) than in other settings (83.83 ± 15.4) ($p = 0.02$).

Symptoms of anxiety and depression

Overall 41% of the sample experienced possible symptoms or symptoms of depression and 20% experienced possible symptoms or symptoms of

Table II. Family care needs measured with FIN (20 items): Means (SD) of importance, prevalence of important needs and prevalence of unmet important needs (N = 223).

FIN-Family Care Needs	Mean ^a (SD)	Important needs ^b %	Unmet needs ^c %
Be assured that the best possible care is being given to the patient	4.9 ± 0.4	100	27
Feel that professionals care about the patient	4.8 ± 0.5	100	20
Have my questions answered honestly	4.7 ± 0.6	97	28
Have explanations given in terms that are understandable	4.7 ± 0.6	97	41
Be informed about changes in the patient's condition	4.7 ± 0.6	90	44
Have information about what to do for the patient at home	4.6 ± 0.8	97	49
Feel there is hope	4.6 ± 0.8	89	38
Know what treatments the patient is receiving	4.6 ± 0.7	94	30
Know what symptoms the treatment or disease can cause	4.6 ± 0.7	90	48
Know specific facts concerning the patients' prognosis	4.6 ± 0.7	90	43
Know the probable outcome of the patients' illness	4.6 ± 0.6	94	47
Be told about changes in treatment plans while they are being made	4.5 ± 0.8	94	41
Know exactly what is being done to the patient	4.5 ± 0.7	90	44
Know when to expect symptoms to occur	4.4 ± 0.7	87	51
Know why things are done for the patient	4.4 ± 0.7	84	44
Feel accepted by the health care professionals	4.1 ± 1.1	71	30
Help with the patient's care	4.0 ± 1.2	66	27
Be told about people who could help with problems	3.9 ± 1.3	72	56
Know the names of the health care professional involved in the patient's care	3.8 ± 1.0	66	27
Have someone be concerned with my health	3.8 ± 1.2	57	47

^aNeeds scale = 1 (not important) – 5 (very important).

^bPrevalence of important needs scored 4 (important) or 5 (very important).

^cPrevalence of important needs not met/partly met scored either 4 or 5 of importance.

Table III. Quality of life mean scores (SD) on Quality of Life Scale Items and total mean (SD) OOL score of family members of cancer patients.

Item	Mean (SD)
1 Material comforts: home, food, conveniences, financial security	5.6 ± 1.2
2 Health: being physically fit and vigorous	5.2 ± 1.4
3 Relationships with parents, siblings and other relatives	5.5 ± 1.3
4 Having and raising children	6.5 ± 0.9
5 Relationship with spouse or significant other	6.3 ± 0.9
6 Relationship with friends	5.8 ± 1.1
7 Helping and encouraging others	5.6 ± 1.1
8 Participating in organizations and public affairs	4.6 ± 1.3
9 Learning: attending school, improving knowledge	5.1 ± 1.2
10 Understanding of self	5.5 ± 1.1
11 Work: job or home	5.7 ± 1.1
12 Creativity/personal expression	4.9 ± 1.2
13 Socializing: meeting other people, doing things	5.0 ± 1.4
14 Reading, music, entertainment	5.3 ± 1.2
15 Participating in active recreation	4.5 ± 1.5
16 Independence, doing for yourself	6.2 ± 0.9
Mean QOL Score	5.5 ± 0.75

anxiety (Table IV). The mean (SD) depression score was 7.3 ± 2.7 and the mean (SD) anxiety score was 5.5 ± 2.8 . No difference was found for background variables except that women had a higher mean (SD) anxiety score (5.9 ± 2.8) than men (4.9 ± 2.7) ($p < 0.01$) and both symptoms differed by time from diagnosis. The mean anxiety scores were higher (6.1 ± 2.8) during years 1–5 than during the first year (5.2 ± 2.6) and more than five years post diagnosis (4.8 ± 2.6) ($p = 0.02$). The same pattern was found for symptoms of depression, the mean depression scores were higher during years 1–5 (8.1 ± 3.2) than during the first year (7.0 ± 2.5) and five years from diagnosis (6.2 ± 1.7) ($p < 0.01$).

Table IV. Symptoms of anxiety and depression measured with HADS: Mean (SD) scores and prevalence of no symptoms, possible symptoms and symptoms, in family members of cancer patients.

Anxiety: mean (SD)	5.5 ± 2.8
Anxiety: prevalence (%)	
Score 0–7 (no symptoms)	79
Score 8–10 (possible symptoms)	13
Score 11–21 (symptoms)	7
Depression: mean (SD)	7.3 ± 2.7
Depression: prevalence (%)	
Score 0–7 (no symptoms)	59
Score 8–10 (possible symptoms)	29
Score 11–21 (symptoms)	12

Relationships between needs, QOL and symptoms of anxiety and depression

QOL was significantly correlated with the number of important needs ($r = 0.26$, $p = 0.01$) and a weak positive relationship was seen between number of important needs met and QOL ($r = 0.25$, $p = 0.01$).

The number of important needs was not found to differ between those who reported no symptoms, possible symptoms and symptoms of either anxiety or depression. Number of important needs not met, however, were found to differ between groups ($p = 0.02$). Those who had no symptoms of anxiety had a mean (SD) of 5.74 ± 5.30 unmet needs, which was lower than the mean (SD) number for those who had symptoms, 9.91 ± 5.82 ($p = 0.02$). Those who had possible symptoms and symptoms did not differ in terms of number of unmet needs.

Similarly, QOL differed based on whether family members had no symptoms, possible symptoms or symptoms of anxiety ($p < 0.01$). Those with symptoms of anxiety reported worse QOL (71.63 ± 18.6) than both those with no anxiety symptoms (86.48 ± 14.12) ($p < 0.01$) and possible symptoms (82.83 ± 12.27) ($p = 0.01$). The same was true for symptoms of depression ($p < 0.01$). Those who reported no symptoms had better QOL (88.84 ± 11.52) than those with possible symptoms (80.63 ± 14.90) ($p < 0.01$) and symptoms (76.00 ± 20.89) ($p < 0.01$).

Discussion

In this study all 20 needs assessed with FIN were considered important. The most important needs were related to patient care and honest and understandable information, and the least important one to the family members own health. This is similar to previous findings using the FIN instrument, highlighting that the focus is on the patient rather than on family members own needs [11,17,22]. A substantial number of important needs (60%), were perceived to be met, and more importantly the two most important needs were most frequently met. However, the prevalence of 40% unmet but important needs in this study is higher than in a previous study from Iceland (33% unmet needs) which was partly conducted in the same setting with the same instrument, but with family members of patients in palliative care [11]. In the present study, almost half the sample received outpatient services and few had home care services, but in our experience, family members are more visible and in more contact with health care professionals when receiving inpatient care or care at home, especially when palliative care is the focus. Neither the number of needs, nor the number of unmet needs differed however, between care sites in this study which is in contrast with previous findings

in the same hospital where family members in specialized palliative care units had more important needs met (74%) than those in acute oncology medical/surgical units (52%) [11]. The lack of difference between care settings in the present study might suggest that the quality of family care has improved in the more acute care settings. From a quality of care perspective it should be a goal that at least 80–90% of important needs are met. This may be achieved by focusing more on specific characteristics of family members who are more likely to have unmet needs. Findings from the present study support previous research in that those groups with unmet needs include women [13], younger family members [13], family members other than spouses [11] and those working outside the home [12]. Even though family members' needs did not differ between care settings, nor with time since diagnosis, family members of patients with metastatic cancer were more likely to have unmet needs than those of patients with localized cancer. It has been reported that needs may vary across specific stages and experiences, including specific transitional time points [13,23]. This must be considered when assessing family members needs and when providing information and support.

The overall QOL of this sample of family members was good. The mean QOL score was similar to what has been reported for a healthy Icelandic population [18] and other healthy populations [19] using the same measure. The score was also similar to what has been reported for Norwegian cancer caregivers in the palliative care phase and Norwegian norms [20]. A positive but weak relationship was found between important needs met and QOL. This is encouraging since this may suggest that by meeting family needs, health care providers can contribute to their QOL.

In the present study, global QOL did not differ based on time from diagnosis. In a recent review findings suggest that QOL varies along the illness trajectory, but most studies of cancer caregivers have predominantly focused on the psychological aspect of QOL [3]. In the present study symptoms of anxiety and depression were both prevalent and differed by time from diagnosis. Mean scores on both the anxiety and depression scale were higher during the second to fifth year after diagnosis, than during the first year or after five or more years. In this context it must be pointed out that patients whose family members participated were not disease free and all receiving medical care. The reason for higher scores on depression and anxiety during the second to fifth year, might be that patients are often completing treatment, or experiencing recurrence or progression during this time, all known points of distress [2,3]. In contrast, during the first year the patient may be

undergoing or completing initial treatment, while patients who are not disease free five years post diagnosis are likely to have already experienced recurrence or progression.

In this study both the prevalence, and the mean scores of anxiety and depression were higher than among the normal Icelandic population [24] and among Icelandic cancer patients starting chemotherapy [25] using the same measure. These higher levels among cancer patient's caregivers than among the general population and cancer patients have also been reported by others using the HADS as a screening tool in the palliative care phase [5,7]. It has, however, been indicated that in general women are more distressed by cancer than men, regardless of role (patient or caregiver) [8]. In this study women had significantly higher anxiety scores than men and higher anxiety was linked with less number of needs met which is in line with other findings showing unmet needs being associated with negative psychological outcomes [6,13].

Family members who experienced symptoms of anxiety and depression reported worse QOL than those who reported no such symptoms. This significant association between QOL and HADS has also been observed by others [15] and indicates that improvements in QOL might be possible by alleviating emotional distress. While QOL in this sample was relatively good, this finding again, highlights the importance of identifying those family members who are at risk of experiencing psychological symptoms.

The findings of this study should be interpreted in light of its main limitations. The design was cross-sectional with small numbers of participants in some care settings, limiting the ability to make comparisons. The FIN needs measure also has some limitations. It was initially developed to measure care needs of families of advanced cancer patients, and might not fully cover all major dimensions of needs. Although, measuring important needs in relation to patient care, information and communication, it does not cover in depth issues in relation to daily activities, financial and social matters, emotional and existential/spiritual needs, which have been included in more recent family needs assessment tools [13].

A major strength of this study is that it is conducted at the main cancer centre in Iceland where the vast majority of cancer patients receive care. In combination with a high response rate it allows for generalizing the findings to family members of cancer patients in Iceland.

In summary, this study contributes to the growing literature on needs, QOL and symptoms of anxiety and depression of family members of cancer patients. In particular, the study provides information about

other aspects of QOL than just psychological distress, and is not only based on family members of patients in more advanced phase of disease. The findings highlight that family members needs should be screened at all times during medical care in combination with symptoms of anxiety and depression.

Acknowledgements

This study was supported by scientific grants from the Icelandic Nurses Association and Landspítali–The National University Hospital of Iceland. The authors would like to acknowledge the support of Kristín A. Sophusdóttir former Director of Oncology Nursing at Landspítali–The National University Hospital of Iceland. The authors would also like to thank Ellen Dögg Sigurjónsdóttir for her help in preparing this manuscript.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

References

- [1] Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. *Psychooncology* 2009. Available from: <http://www.interscience.wiley.com.10.1002/pon.1670>. Accessed date 30 June 2010.
- [2] Pitceathly C, Maguire P. The psychological impact of cancer on patients' partners and other key relatives: A review. *Eur J Cancer* 2003;39:1517–24.
- [3] Kim Y, Given BA. Quality of life of family caregivers of cancer survivors: Across the trajectory of the illness. *Cancer* 2008;112(11 Suppl):2556–68.
- [4] Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns* 2008;71:251–8.
- [5] Gough K, Hudson P. Psychometric properties of the Hospital Anxiety and Depression Scale in family caregivers of palliative care patients. *J Pain Symptom Manage* 2009;37:797–806.
- [6] Molassiotis A, Wilson B, Blair S, Howe T, Cavet J. Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psychooncology* 2010. Available from: <http://www.interscience.wiley.com.10.1002/pon.1710>. Accessed date 30 June 2010.
- [7] Grov EK, Dahl AA, Moum T, Fosså SD. Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 2005;16:1185–91.
- [8] Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne, JC. Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychol Bull* 2008;134:1–30. doi:10.1037/0033-2909.134.1.1.
- [9] Kristjanson LJ, White K. Clinical support for families in the palliative care phase of hematologic or oncologic illness. *Hematol Oncol Clin North Am* 2002;16:745–62.
- [10] Wen KY, Gustafson DH. Needs assessment for cancer patients and their families. *Health Qual Life Outcomes* 2004. Available from: <http://www.hqlo.com/content/2/1/11>. Accessed date 30 June 2010.
- [11] Friðriksdóttir N, Sigurdardóttir V, Gunnarsdóttir S. Important needs of families in acute and palliative care settings assessed with the family inventory of needs. *Palliat Med* 2006;20:425–32.
- [12] Park SM, Kim YJ, Kim S, Choi JS, Lim HY, Choi YS, et al. Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's work-force performance. *Support Care Cancer* 2010;18:699–706.
- [13] Kim Y, Kashy DA, Spillers RL, Evans TV. Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psychooncology* 2010;19:573–82.
- [14] Hwang SS, Chang VT, Alejandro Y, Osenenko P, Davis C, Cogswell J, et al. Caregiver unmet needs, burden, and satisfaction in symptomatic advanced cancer patients at a Veterans Affairs (VA) medical center. *Palliat Support Care* 2003;1:319–29.
- [15] Iconomou G, Viha A, Kalofonos HP, Kardamakis D. Impact of cancer on primary caregivers of patients receiving radiation therapy. *Acta Oncol* 2001;40:766–71.
- [16] Sharpe L, Butow P, Smith C, McConnell D, Clarke S. The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psychooncology* 2005;14:102–14.
- [17] Kristjanson LJ, Atwood J, Degner LF. Validity and reliability of the family inventory of needs (FIN): Measuring the care needs of families of advanced cancer patients. *J Nurs Meas* 1995;3:109–26.
- [18] Guðmundsson M, Hrafnsson ÓV. *Prófræðilegir eiginleikar Lífsgæðakvarðans (QOLS)*. [BA]. Reykjavík: University of Iceland; 2007.
- [19] Burckhardt CS, Anderson KL. The Quality of Life Scale (QOLS): Reliability, validity, and utilization. *Health Qual Life Outcomes* 2003;1:60. Available from: <http://hqlo.com/content/1/1/60>. Accessed date 30 June 2010.
- [20] Grov EK, Dahl AA, Fossa SD, Wahl AK, Moum T. Global quality of life in primary caregivers of patients with cancer in palliative phase staying at home. *Support Care Cancer* 2006;14:943–51.
- [21] Schaaber U, Smári J, Óskarsson H. Comparison of the hospital anxiety and depression rating scale (HAD) with other depression and anxiety rating scales. *Nordisk Psychiatrisk Tidsskrift* 1990;44:507–12.
- [22] Ross S, Mosher CE, Ronis-Tobin V, Hermele S, Ostroff JS. Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Support Care Cancer* 2010;18:171–8.
- [23] DuBenske LL, Wen KY, Gustafson DH, Guarnaccia CA, Cleary JF, Dinuer SK, et al. Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care* 2008;6:265–72.
- [24] Magnusson A, Axelsson J, Karlsson MM, Óskarsson H. Lack of seasonal mood change in the Icelandic population: Results of a cross-sectional study. *Am J Psychiatry* 2000;157:234–8.
- [25] Saevarsdóttir T, Friðriksdóttir N, Gunnarsdóttir S. Quality of life and symptoms of anxiety and depression of patients receiving cancer chemotherapy: Longitudinal study. *Cancer Nurs* 2010;33:E1–10.