Original Article

Unmet needs and quality of life of family caregivers of cancer patients in South Korea

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ABSTRACT

Objective: The purpose of this study was to investigate the levels of unmet needs and quality of life (QOL) among family caregivers (FCs) of cancer patients and to characterize the relationship between unmet needs and QOL. **Methods:** A descriptive correlation design was used. Data were collected by convenience sampling during 2013 from 191 FCs of cancer patients who visited an outpatient cancer center in a general hospital in Korea. The comprehensive needs assessment tool for cancer-caregivers and the Korean version of the Caregiver QOL Index-Cancer were used to measure unmet needs and QOL, respectively. **Results:** FCs of cancer patients had a variety of unmet needs with prevalence ranged from 57.0% to 88.9%, depending on the domain. The domain with the highest prevalence of unmet needs was healthcare staff, followed by information/education. The mean QOL score was 74.62, with a possible range of 0-140.

A negative correlation was found between unmet needs and QOL. Stepwise multiple regression analysis showed that unmet needs relating to health/psychological problems, practical support, family/social support, in addition to household income, cohabitation with the patient, and patient's age, explained 52.7% of the variance in QOL. The most influential factor was unmet needs relating to health/psychological problems, which accounted for 35.7% of the variance. **Conclusions:** The results of this study indicate that oncology professionals need to develop interventions to improve the QOL of FCs by focusing not only on information/educational needs of patient care but also on physical and psychological needs of FCs.

Key words: Neoplasms, family caregivers, health services needs and demand, quality of life

Introduction

Cancer is no longer considered an acute disease, as the survival rates of cancer, have increased due to the improvements in cancer diagnosis, treatment, and care. For example, in South Korea, the 5-year survival rate of cancer has increased from 44.4% in 2000 to 68.1% in 2012.[1]

Cancer, however, still brings many physical, emotional, social, and spiritual changes to cancer patients, and the effects of such changes may be profound and long-lasting. Cancer also brings many changes to family members. Family caregivers (FCs), who are major but unpaid care partners, are affected most by meeting multi-dimensional needs of cancer patients. They play a pivotal role in monitoring treatment, managing treatment-related symptoms, and providing emotional, social, and spiritual support to their patient.[2-4] In recent years, the role of FCs has become more diverse and involved, as the duration of hospital stays of cancer patients has shortened while outpatient care services have expanded with improved anti-cancer drugs.[5] Thus, some of the FCs even have to take responsibility for managing intravenous central lines or infusion pumps for medication at home which were once provided by oncology professionals.

Most studies in FCs of cancer patients reported diverse problems, ranging from diminished physical health and

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psychological distress to adverse impact on work.[6] These problems lead to increasing burden[7,8] and decreasing quality of life (QOL).[2,9] A review study[10] indicated that QOL depends on the changes in circumstances of both patients and caregivers. QOL of FCs improves after patients have completed treatment, while it was found to remain low during treatment. Earlier stages of cancer and positive responses to treatment were found to be positively associated with the caregiver's QOL. QOL of FCs of patients receiving palliative care is lower than patients receiving curative treatment.[11] In the dimension of FCs, social factors, such as marital satisfaction and social support, contribute to higher caregiver QOL,[12,13] while loss of physical strength, excessively demanding caregiving role, feelings of being burdened, and psychological distress of FCs contribute to a lower caregivers' QOL.[13-18] The duration of the caregiving role and the impact of caregiving on caregivers' lives are also related to lower caregiver QOL.[13,18,19] In addition, the unmet needs of FCs are related to higher levels of distress and a poorer QOL.[3,7,20,21] Most FCs take their role under sudden circumstances without appropriate time to prepare which requires diverse and multidimensional needs, ranging from informational needs to physical and psychological needs, and their needs are not appropriately met.[2-4,7,8,20,21] But most of these studies have conducted in Western societies, requiring further studies in diverse regions with an ethnically diverse range of population to identify what kinds of unmet needs are prevalent and how much unmet needs were related to QOL of FCs.

The purpose of this study was to examine the unmet needs and QOL of FCs of cancer patients in South Korea. The specific aims were as follows:
1. To examine the extent of unmet needs and the level of QOL.
2. To examine the relationship between unmet needs and QOL.
3. To identify factors that influence QOL.

Materials and Methods

Design and sample

This was a correlational survey study. The sample size was calculated using the G-power 3.1 program by the Heinrich Heine Universität, Düsseldorf. A total of 103 participants were needed for a medium effect size of 0.15, a significance level of 0.05, a verification power (1-β) of 0.8, and 7 predictive variables.

The inclusion criteria of this study were primary FCs of cancer patients who were 18 years old and above and receiving treatment in the outpatient department. FCs were selected using a two-step process. First, cancer patients who were 18-year-old and above were recruited using convenience sampling. Then, the patients were asked to identify their caregivers to participate in the study.

Instruments

Demographic and patient-related characteristics

Based on previous studies in the literature, the survey used in this study included questions about gender, age, religion, education, employment, household income, relationships with the patient, cohabitation with the patient, and duration of care. Patient-related characteristics were included, such as age, type of cancer, cancer stage, cancer trajectory, and current treatment. Medical records were used to identify the current stage of treatment, divided into three categories: Treatment stage, palliative stage, and disease-free status.

Unmet needs

Unmet needs were measured with the comprehensive needs assessment tool for cancer-caregivers developed by Shin et al.[22] It is composed of 41 items belonging to seven domains of unmet needs. For each item, an answer was given using a four-point Likert scale. Each item was assigned a score ranging from 0 if the unmet need was not relevant, not needed, or if the caregiver was satisfied with the support, to 3 if it was very much needed. The total possible score ranged from 0 to 123, with a higher score indicating a greater amount of unmet needs. When developed, the Cronbach's α value corresponding to the instrument as a whole was found to be 0.96, while the Cronbach's α value of the sub-domains ranged from 0.75 to 0.95. In this study, the Cronbach's α value was found to be 0.96 overall, ranging from 0.80 to 0.94 in the sub-domains.

Quality of life

Quality of life was measured using the Korean version of the Caregiver QOL Index-Cancer, developed by Weitzner et al.[23] and translated and verified by Rhee et al.[24] It consists of 35 items: 10 items dealing with feelings of being burdened, 7 items dealing with disruption, 7 items dealing with positive adjustment, 3 items dealing with financial concerns, and 8 independent items. Answers were provided for each item using a five-point Likert scale ranging from 0, corresponding to "not at all," to 4, corresponding to "very much." The total score ranged from 0 to 140, with a higher score indicating higher QOL. Rhee et al.[24] found that Cronbach's α value for this instrument was 0.90, and in our study, the overall Cronbach's α value was likewise found to be 0.90, ranging from 0.79 to 0.87 in the sub-domains.

Data collection

The data were collected during the 2 weeks in October 2013 in an outpatient department in a cancer center located in Seoul, South Korea, using convenience sampling. The data were collected by seven study assistants who were trained in data collection for an hour. Study participants were informed about the purpose of the study, selection criteria, and procedures, including how to fill the questionnaires. The questionnaires required approximately 20 min to complete. A total of 240 questionnaires were distributed, and 205 were returned. In the final analysis, 191 questionnaires were used, due to incomplete response or refusal to participate in the study (response rate = 79.6%).

Statistical analysis

The data were analyzed using SPSS 21.0 (IBM Corp., Armonk, NY, USA). First, descriptive statistics was used to analyze demographic and patient-related characteristics as well as the data regarding unmet needs and QOL. Second, the Chi-squared test, t-test, one-way ANOVA, and Scheffé $post-hoc$ test were performed to identify differences in QOL based on demographic and patient-related characteristics. Third, the Pearson's correlation coefficient was used to assess the relationship between unmet needs and QOL. Finally, multiple regression analysis was carried out, using seven domains of unmet needs, in order to ascertain which domain contributed most to variance in QOL and to identify the relative contribution of each domain. Reliability was measured using Cronbach's α.

Ethical considerations

Before collecting data, the study proposal was approved by the institutional review board of the institution where the study was performed (institutional review board number: H-1309-030-517). The FCs were informed about the purpose of the study and were assured that they were able to withdraw from the study at any time and that personally identifying information would not be collected. They signed the consent form voluntarily.

Results

Characteristics of the participants

With regard to the demographic characteristics of the participants, 113 participants (59.2%) were female, and the mean age was 49.06 years (±12.35). About one half was spouses and employed, and the majority of participants were religious and living with the patients they cared for and had cared for their patients for <1 year [Table 1].

Turning to the patient-related characteristics, the mean age of the patients was 56.85 years (±12.85), ranging from 18 to 86 years. Fifty-two patients (27.2%) were diagnosed with breast cancer and lung cancer, respectively [Table 2]. Seventy-nine patients (41.4%) were diagnosed with advanced-stage cancer while 61 (31.9%) were in the terminal stage. In terms of cancer trajectory, 82 patients (42.9%) were in the palliative stage while 76 (39.8%) were in the treatment stage. At the time of the study, most patients (75.9%) were receiving chemotherapy.

Unmet needs

As shown in Table 3, the total mean score of unmet needs of the participants was 61.30 ± 26.62, with a possible range of 0-123. The overall mean item score was 1.50 ± 0.65, with a range from 0.83 to 2.32 depending on the item. The domain with the highest unmet need score was "healthcare staff," followed by "information/education." The item with the highest unmet need score was "seeing a doctor quickly and easily when in need" (2.32 ± 0.87), followed by "information about the current status of the patient's illness and its future course" (2.26 ± 0.92).

Across the various domains, the percentage of the participants who expressed unmet needs ranged from 57% to 88.9%. The domain with the highest prevalence of unmet needs domain was healthcare staff (88.9%), followed by information/education (84.0%) and hospital facilities/services (78.8%).

Quality of life

As shown in Table 4, the mean QOL score was 74.62 ± 20.54), with a possible range of 0-140. The mean score per item ranged from 0.78 ± 1.13 to 2.99 ± 1.15. The lowest QOL scores were found in the domain dealing with feelings of being burdened (1.95 ± 0.86), followed by the domain dealing with positive adaptations (2.05 ± 0.67). The item with the lowest mean score was the death of a patient, followed by "social support." In contrast, the item with the highest mean was "focus of caregiving," followed by "guilt" and "frustration."

Table 1 shows that QOL varied significantly according to household income ($P = 0.006$), whether the caregiver lived with the patient ($P = 0.0009$) and the duration of care ($P = 0.006$). Table 2 shows that QOL varied according to the patient's age ($P = 0.032$), and the cancer stage ($P = 0.008$). The Scheffé test revealed that the participants with a monthly income <3 million Korean won had a lower QOL than those with an income more than 5 million Korean won. As well, participants

Table 1: QOL according to the demographic characteristics of the participants (n = 196)						
Characteristics	Category	n (%)	Mean ± SD	F value or t value	P	Scheffé post-hoc test
Gender	Male	78 (40.8)	77.3±19.0	1.528	128	
	Female	113 (59.2)	72.7±21.4			
Age (years)	≤39	37 (19.4)	78.9±23.7	0.917	0.434	
	40-49	58 (30.4)	72.6±19.4			
	50-59	58 (30.4)	75.5±21.6			
	≥60	38 (19.9)	72.3±17.0			
Religious	Yes	136 (71.2)	73.2±20.9	1.512	0.132	
	No	55 (28.8)	78.1±19.4			
Education	≤Middle school	22 (11.5)	67.3±18.0	2.004	0.138	
	High school	69 (36.1)	73.9±18.6			
	≥College	100 (52.4)	76.7±22.1			
Employment	Yes	102 (53.4)	75.0±20.7	0.306	0.760	
	No	89 (46.6)	74.1±20.4			
Household income (million won)	<1 (a)	25 (13.1)	67.5±20.9	4.320	0.006*	a<d
	1-3 (b)	74 (38.7)	72.8±22.7			b<d
	3-5 (c)	54 (28.3)	73.6±17.9			
	>5 (d)	38 (19.9)	84.4±16.3			
Relationship with patient	Spouse	98 (51.3)	72.8±19.1	0.617	0.605	
	Parent	26 (13.6)	76.2±17.5			
	Children	53 (27.7)	76.2±23.4			
	Other	14 (7.4)	78.9±24.6			
Living with patient	Yes	140 (73.3)	72.3±20.1	2.638	0.009*	
	No	51 (26.7)	81.0±20.5			
Duration of care (years)	<1 (a)	119 (62.3)	74.8±20.2	4.244	0.006*	b>d
	1-3 (b)	53 (27.7)	77.3±19.9			c>d
	3-5 (c)	9 (4.7)	79.7±20.0			
	>5 (d)	10 (5.2)	53.4±18.4			

*P < 0.05. SD: Standard deviation, QOL: Quality of life

Table 2: QOL according to the patient-related characteristics (n = 196)						
Characteristics	Category	n (%)	Mean ± SD	F value or t value	P	Scheffé post-hoc test
Patient's age (years)	≤49	53 (27.7)	71.3±18.1	2.988	0.032	
	50-59	61 (31.9)	79.0±20.8			
	60-69	47 (24.6)	77.3±19.8			
	≥70	30 (15.7)	67.4±23.2			
Type of cancer	Breast	52 (27.2)	77.0±19.9	0.623	0.683	
	Lung	52 (27.2)	73.2±22.3			
	Lymphoma	20 (10.5)	72.0±16.7			
	Colon	16 (8.4)	68.6±22.7			
	Stomach	11 (5.8)	77.5±22.7			
	Other	40 (20.9)	76.3±19.7			
Cancer stage	Early stage (a)	35 (18.3)	85.1±16.2	4.024	0.008	a>b
	Advanced stage (b)	79 (41.4)	72.6±20.9			a>c
	Terminal stage (c)	61 (31.9)	72.6±21.4			
	Unknown (d)	16 (8.4)	69.4±17.8			
Cancer trajectory	Treatment stage	76 (39.8)	76.3±19.0	1.708	0.184	
	Palliative stage	82 (42.9)	71.6±22.4			
	Disease-free status	33 (17.3)	78.4±18.5			
Current treatment	Chemotherapy	145 (75.9)	74.9±20.7	0.285	0.776	
	Other	46 (24.1)	73.9±20.1			

*P < 0.05. SD: Standard deviation, QOL: Quality of life

with more than 5 years of caring experience had a significantly lower QOL than those with 1-5 years of caring experience. The participants caring for cancer patients with advanced- or terminal-stage cancer had a lower QOL than those caring for patients with early-stage cancer.

Table 3: Scores of unmet needs (n = 191)					
Domain	**No need or satisfied, *n* (%)**	**Low need, *n* (%)**	**Moderate need, *n* (%)**	**High need, *n* (%)**	**Mean ± SD**
Health/psychological problems	57.8 (30.3)	50.0 (28.8)	43.3 (22.7)	33.0 (17.3)	1.27±0.86
Family/social support	74.6 (39.1)	58.8 (30.8)	36.0 (18.9)	21.2 (11.1)	1.02±0.83
Healthcare staff	21.1 (11.1)	42.0 (22.0)	54.8 (28.7)	73.0 (38.2)	1.94±0.84
Information/education	30.5 (16.0)	37.6 (19.7)	53.6 (28.1)	68.5 (35.9)	1.84±0.80
Religious/spiritual support	82.0 (43.0)	47.0 (24.6)	38.5 (20.2)	23.5 (12.3)	1.02±0.96
Hospital facilities/services	40.3 (21.2)	45.5 (23.8)	44.5 (23.3)	60.3 (31.6)	1.56±0.81
Practical support	67.4 (35.3)	44.3 (23.2)	36.5 (19.1)	42.1 (22.1)	1.28±0.81
Total scores=61.30±26.62				Item mean=1.50±0.65	

SD: Standard deviation

Table 4: Scores of QOL (n = 191)		
Domain	**Item**	**Mean ± SD**
Burdens		1.95±0.86
	Death of patient	0.78±1.13
	Level of stress	1.63±1.29
	Sadness	2.47±1.31
	Guilt	2.78±1.18
	Frustration	2.75±1.22
	Nervousness	2.24±1.33
	Impact of illness on family	1.95±1.25
	Adverse effect of treatment	1.16±1.19
	Deterioration of patient	1.22±1.34
	Future outlook	2.51±1.31
Disruptiveness		2.43±0.88
	Alteration in daily routine	2.33±1.13
	Impact on daily schedule	2.59±1.17
	Maintenance of outside activities	2.44±1.22
	Patient's eating habits	2.56±1.17
	Transportation	2.07±1.30
	Responsibility for patient's care	2.51±1.26
	Change in priorities	2.47±1.24
Positive adaptation		2.05±0.67
	Outlook on life	2.18±1.35
	Spirituality	1.48±1.44
	Social support	0.94±1.15
	Relationship with patient	2.45±1.11
	Focus of caregiving	2.99±1.15
	Family communication	2.30±1.13
	Family support	1.98±1.20
Financial concerns		2.22±1.12
	Financial strain	2.27±1.31
	Concern about insurance	2.31±1.33
	Economic future	2.08±1.35
Single items		
Disruption of sleep		2.42±1.20
Satisfaction with sexual function		1.23±1.21
Day-to-day focus		2.28±1.25
Mental strain		2.23±1.26
Informed about illness		2.45±1.03
Protection of patient		2.07±1.40
Management of patient's pain		2.01±1.35
Family interest in caregiving		2.77±1.25
Total mean score=74.62±20.54		Item mean=2.14±0.59

SD: Standard deviation

Correlations between unmet needs and quality of life

Quality of life was negatively correlated with the extent of unmet needs ($r = -0.604$, $P < 0.01$). Further analysis revealed that QOL was significantly correlated with all 7 domains of unmet needs. The most highly correlated domain was that of health/psychological problems ($r = -0.596$, $P < 0.01$), followed by family/social support ($r = -0.588$, $P < 0.01$), practical support ($r = -557$, $P < 0.01$), information/education ($r = -0.451$, $P < 0.01$), hospital facilities/services ($r = -0.417$, $P < 0.01$), religious/spiritual support ($r = -0.359$, $P < 0.01$), and healthcare staff ($r = -0.294$, $P < 0.01$).

Factors influencing quality of life

Stepwise multiple regression analysis showed that unmet needs relating to health/psychological problems, practical support, family/social support, household income, cohabitation with the patient, and patient's age explained 52.7% ($R^2 = 52.9$) of the variance in QOL [Table 5]. The most significant domain of unmet needs was health/psychological problems, which explained 35.7% of QOL variance, followed by practical support and family/social support. The regression model determined by this study was statistically significant ($F = 34.487$, $P < 0.001$).

Discussion

Our findings demonstrate that unmet needs of FCs of cancer patients are diverse as suggested by previous studies[2-4,7,8,20,21] and that the prevalence of unmet needs is high. In this study, the prevalence of unmet needs ranged from 57.0% to 88.9%, depending on the domain. These prevalence rates are higher than those found in another study,[20] which reported prevalence rates ranging from 18.9% to 67.9% in Western countries. This discrepancy may be related to the differences in participants. In this study, most of the participants were the FCs of cancer patients with advanced or terminal-stage cancer, whereas

Table 5: Factors influencing QOL ($n = 191$)							
Variable	Unstandardized coefficients		Standardized coefficients	R^2	Cumulative R^2	t	P
	B	SE*	β				
Constant	3.246	0.182				17.849	<0.001
Health and psychological problems	−0.206	0.056	−0.301	0.357	0.357	−3.710	<0.001
Practical support	−0.246	0.044	−0.337	0.094	0.451	−5.588	<0.001
Family/social support	−0.132	0.057	−0.186	0.025	0.476	−2.308	0.022
Income	0.002	0.001	0.133	0.018	0.494	2.582	0.011
Live together	−0.004	0.001	−0.150	0.017	0.511	−2.909	0.004
Patient age	−0.007	0.002	−0.143	0.018	0.529	−2.710	0.007
*SE: Standard errors, QOL: Quality of life							

the majority of participants in the earlier study cared for patients with early-stage cancer.

The highest rates of unmet needs were found in the domains of healthcare staff and information/education, corresponding to the results of previous studies.[7,8,20] This strongly indicates that both FCs and cancer patients depend heavily on oncology professionals for informational and educational support. Thus, it would be necessary for oncology professionals to be prepared to communicate effectively with caregivers by providing appropriate information in an empathetic manner. Furthermore, interventions including skills training and therapeutic counseling, would be helpful not only to meet the unmet needs of FCs but also to improve their QOL.[25,26]

In our study, the overall QOL score was 74.6, with a possible range of 0-140. This is a relatively low score but was somewhat higher than the score of 69.6 found among FCs of cancer patients undergoing outpatient-based chemotherapy in South Korea, using the same instrument.[17] However, the items that received relatively low QOL scores, such as "death of patient," "adverse effects of treatment," and "deterioration of patient" were similar to this study.[17] This suggests that FCs experience a very high burden in relation to the patient's condition. This also suggests that FCs burden increase as patient's functional status declines.[11,27]

Other items that received relatively low QOL scores were social support, satisfaction with sexual function, spirituality, and family support. This is also consistent with the previous findings,[17] suggesting that FCs in Korea do not receive enough support from either other family members or society. In contrast, the item that received the highest QOL scores was the "focus of caregiving." This suggests that FCs need to be encouraged to view their involvement in cancer care as meaningful and as a personal growth experience, in order to support them in positively adjusting to their circumstances and in maturing through the experience of caregiving.

Our study demonstrates a low QOL among low-income caregivers, consistent with the previous studies.[9,10,28,29] In Korea, almost all of the population is covered by the National Health Insurance; inpatients, including cancer patients, pay 20% of health care charges and outpatients pay 50% of them, although some special medical services and drugs are not covered. Our study shows that low-income FCs with the cancer patient in Korea with National Health Insurance still suffer from health care costs, requiring customized healthcare policy to improve outcomes for both patients and caregivers. This study also shows a low QOL among caregivers living with cancer patients,[30] and caregivers of cancer patients with advanced or terminal-stage illness.[2,11,14] Thus, more attention must be given to these vulnerable groups, in order to encourage them to obtain adequate rest and not feel obligated to deal with the patient's condition at all times. As well, oncology professionals must pay attention to caregivers who have been providing care for a long period.[13,28]

The results from this study have shown that the extent of unmet needs was highly correlated to QOL. Higher unmet needs scores corresponded to lower QOL levels. However, as indicated in the previous studies,[10,20] QOL was influenced by unmet needs in the domains of "health/psychological problems," "practical support," and "family/social support," which showed relatively low prevalence rates. This indicates that FCs may suffer from their own physical and psychological health problems, but they do not feel able to discuss them because they are afraid to draw attention to themselves, thereby distracting from the care of the cancer patients that they care for these findings clearly suggest that it is necessary to include the physical and psychological health of FCs when developing interventions,[8] although they report less unmet needs in these domains. Practical support and family/social support should also be reinforced to improve the QOL of FCs. In particular, low-income FCs living with patients with advanced or terminal-stage cancer and those who have been providing care for long periods must be supported by

other family members as well as oncology professionals. Utilizing respite care and self-help group activities would help to enhance the QOL of FCs. For FCs, sharing their experiences in self-help groups could relieve their feelings of being burdened. Identifying a "caregiver champion"[26] would be an important step in empowering caregivers. As many authors have noted,[2,25,26] such programs must be designed to help caregivers, tailored to their needs, and focused on their physical and psychosocial care.

The study has several limitations. The results of the study may not be generalizable to other samples of FCs of cancer patients from other areas of Korea or other countries. Second, the sample was drawn from caregivers who visited the outpatient Department of Medical Oncology. Thus, the results of the study may not be applicable to caregivers visiting surgical outpatient departments and caregivers of patients in inpatient settings. To achieve a more representative sample, in light of the millions of cancer caregivers at home, is greatly needed.

Conclusion

This study demonstrated that FCs of cancer patients have a variety of unmet needs with high prevalence and that unmet needs strongly predicted their QOL. The most distinctive findings of this study were related to the impact of health/psychological unmet needs on the QOL of caregivers. That is, the domains of unmet needs with relatively low prevalence rates influenced QOL rather than the domains in which unmet needs were commonly reported. This clearly indicates that oncology professionals must pay attention to the physical and psychological needs of FCs, even though they typically do not seek for help, in addition to continually providing information regarding patient care. Psychoeducational interventions and therapeutic counseling must be included to improve QOL of FCs of cancer patients.

The results of our study suggest that the oncology care system must strive to skillfully incorporate family members. Respite care and self-help groups for FCs must also be extended to relieve their unmet needs and improve their QOL.

Acknowledgments

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