RESEARCH ARTICLE

Quality of Life of Family Members Living with Cancer Patients

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Abstract

    Background: Due to the rapid progress of industrialization, the expansion of the nuclear family, and an increase in women's social activities, the burden of care of cancer patients has increased, so that all family members are now involved in care. We compared the health-related quality of life (HRQOL) between members of families of cancer patients (hereafter, cancer families) and members of cancer-free families (non-cancer families). Materials and Methods: The data were from the Community Health Survey (2012). The study population included respondents at least 30 years of age. Data were adjusted for the following covariates: sex, age, education, marital status, household income, economic activity, household type, chronic disease, and perceived health status. Frequency analysis, analyses of variance, and multiple linear regression analysis were performed. Results: Among 163,495 respondents, 3,406 (2.1%) were part of a cancer family and 160,089 (97.9%) were part of a non-cancer family. Cancer families had lower EQ-5D scores than non-cancer families. However, by subgroup, the scores had significant association between cancer and non-cancer families only for females and for those who worked. Conclusions: There was a significant relationship between HRQOL scores and being a family member of a cancer patient. This indicates that the responsibility for care has been extended to the entire family, not only the primary caregiver.

Keywords: Cancer patients - care burden - health- related quality of life - Korea

Introduction

    Cancer is a disease that threatens the health and lives of patients. Because of aging and changes in lifestyle, the incidence of cancer in 2012 in Korea was about 445.3 per 100,000 population, and continues to increase annually. In addition, the cancer mortality rate increased from 23.0 per 100,000 population in 2000 to 149.0 per 100,000 population in 2011 (Korea National Cancer Information Center, 2014). Thus, various efforts at the national level have focused on the early diagnosis and treatment of cancer, which has resulted in a gradual increase in survival time after diagnosis. Indeed, more than half of cancer patients survive for longer than 5 years, and cancer is considered as a chronic disease that needs continuous management (Han et al., 2006). In addition, the burden on cancer patients' caregivers has increased (Vanderwerker et al., 2005; Bowman et al., 2006).

    Cancer patients may experience physical and psychological distress. However, distress due to cancer is not limited to the patient (Grov et al., 2005). The caregivers of cancer patients may also report various problems, including economic problems related to treatment, psychological distress, restriction of social activities, and diminished physical health (Hoga et al., 2008; Kim and Given, 2008). These problems can be of prolonged duration and may be aggravated by changes in the patient's condition (Given et al., 2004; Given and Northouse, 2011).

    The physical and mental struggles of caregivers in turn reduce the well-being of cancer patients, which has a negative effect on cancer treatment (Stenberg et al., 2010; Muhamad et al., 2011; Hong et al., 2012). Thus, it is essential to ensure that caregivers are well-prepared and to promote their quality of life (QOL) because they play an important role in helping patients regain or maintain their health (Northouse et al., 2012). In addition, basic studies on the management of the QOL of members of the families of cancer patients (hereafter, cancer families) are needed.

    Studies on the QOL of cancer families have been performed. However, they have focused on QOL related to psychological distress of only caregivers, not other family members. With the rapid progress of industrialization, the expansion of the nuclear family, and an increase in women's social activities, the burden of care has increased and today all family members are involved in care of cancer patients (Kim and Yu, 2008). In addition, few studies have used representative samples and health-related quality of life (HRQOL) as an outcome variable.

    In the present study, we assessed the HRQOL of cancer families compared to the family members of non-cancer patients (hereafter, non-cancer families).

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Materials and Methods

Study population

This was a cross-sectional study using secondary data from the Community Health Survey (2012) administered by the Korea Centers for Disease Control and Prevention. The Community Heath Survey included nationally representative samples of Koreans aged 19 years or older. The survey is conducted annually by trained interviewers who conducted one-on-one visits, and the questionnaire contains questions relating to health behavior, health care utilization, socioeconomic status, and so forth. This study included adults at least 30 years of age who responded to the survey. People with missing variables, one-person households, and/or a history of cancer were excluded. Our analysis utilized a final sample size of 163,495.

Measures

We used the EuroQOL Five Dimensions (EQ-5D) Index, which is commonly used to measure HRQOL as an outcome variable. The original EQ-5D Index has scores from 0 to 1. However, for ease of visualization, the EQ-5D score was multiplied by 100.

The variable of interest was being part of a cancer family, which was categorized as yes or no. A family was defined as individuals living together, and cancer patients were defined as individuals who had been diagnosed with, and treated for, cancer by a physician. In addition, we controlled for possible covariates of HRQOL. Respondents' household income levels were classified into four groups by calculating quartiles. The chronic diseases evaluated included hypertension, diabetes mellitus, hyperlipidemia, stroke, myocardial infarction, angina, arthritis, osteoporosis, asthma, hepatitis B, and depression, which had been diagnosed and treated by a physician. Perceived health status was evaluated by means of the following five options: very good, good, fair, poor, and very poor. Respondents answering "*very good*" or "*good*" were categorized into the "*good*" group. The others were categorized into the "*poor*" group.

Table 1. General Characteristics and Mean EQ-5D Scores of the Study Population

	N	(%)	Mean	±SD	P-value
Part of a cancer family					
No	160,089	(97.9)	94.11	± 11.22	0.0102
Yes	3,406	(2.1)	92.25	± 12.78	
Sex					
Men	76,864	(47.0)	95.59	± 10.13	<.0001
Women	86,631	(53.0)	92.72	± 12.01	
Age					
30-39	32,671	(20.0)	98.05	± 5.32	<.0001
40-49	39,624	(24.2)	97.41	± 6.52	
50-59	37,867	(23.2)	95.56	± 8.90	
60-69	27,671	(16.9)	91.80	± 12.31	
≥ 70	25,662	(15.7)	84.11	± 16.73	
Education					
Less than middle school	41,381	(25.3)	86.85	± 15.44	<.0001
High or middle school graduate	74,392	(45.5)	95.74	± 9.03	
College graduate	47,722	(29.2)	97.73	± 6.12	
Marital status					
Married	138,711	(84.8)	94.64	± 10.54	<.0001
Divorce, separation, bereavement	16,729	(10.2)	88.03	± 15.48	
Unmarried	8,055	(4.9)	96.97	± 8.47	
Household income					
Q1(Low)	38,243	(23.4)	88.16	± 15.38	<.0001
Q2	43,110	(26.4)	94.41	± 10.61	
Q3	42,055	(25.7)	96.34	± 8.19	
Q4(High)	40,087	(24.5)	96.98	± 7.24	
Economic activity					
No	62,923	(38.5)	89.92	± 14.67	<.0001
Yes	100,572	(61.5)	96.68	± 7.33	
Household type					
First generation	53,863	(32.9)	91.73	± 13.06	<.0001
Second generation	90,861	(55.6)	95.72	± 9.38	
Third generation	18,771	(11.5)	92.81	± 12.54	
Chronic disease					
0	109,421	(66.9)	96.69	± 7.79	<.0001
1	31,652	(19.4)	91.51	± 12.80	
≥ 2	22,422	(13.7)	84.94	± 16.45	
Perceived health status					
Poor	101,012	(61.8)	91.62	± 13.03	<.0001
Good	62,483	(38.2)	98.04	± 5.64	
Total	163,495	(100.0)	94.07	± 11.26	

Statistical analysis

In the analysis of the association between HRQOL and being part of a cancer family, the following variables were adjusted for: sex, age, education, marital status, household income, economic activity, household type, chronic disease, and perceived health status. We first examined the general characteristics of the study population with frequency analysis statistics. Next, in order to assess the average EQ-5D scores according to the different independent variables, we conducted analyses of variance (ANOVA).

Finally, to evaluate the relationship between cancer families and EQ-5D score, we performed a regression analysis. In addition, subgroup analyses were carried out to examine possible associations between being part of a cancer family and the EQ-5D score, with reference to particular subsets of the study population. SAS version 9.3 (SAS Institute, Inc., Cary, NC, USA) was used for all analyses.

Results

Table 1 shows the general characteristics and mean EQ-5D scores of the study population. Among 163,495 respondents, 3,406 (2.1%) were part of a cancer family and 160,089 (97.9%) were part of a non-cancer family. Total average of EQ-5D in study population was 94.07. The average EQ-5D scores of non-cancer families was significantly higher than that of cancer families (non-cancer families: 94.11, cancer families: 92.25). In addition, men had higher value in EQ-5D score than women (men: 95.59, women: 92.72).

Table 2 shows the results of regression analyses of the association between being part of a cancer family and EQ-5D score. We adjusted for all variables shown in the table simultaneously. Cancer families showed less relation with increasing EQ-5D score than non-cancer families (cancer families: β=-0.424, P=0.0210). Women also showed less relation with increasing EQ-5D score than men (women:

Table 2. Association between Family Type and EQ-5D Score

	Health-related of quality of life		
	β*	S.E	p-value
Part of a cancer family			
No	Ref	-	-
Yes	-0.424	0.184	0.021
Sex			
Men	Ref	-	-
Women	-0.688	0.055	<.0001
Age			
30-39	Ref	-	-
40-49	-0.261	0.047	<.0001
50-59	-0.322	0.063	<.0001
60-69	-0.943	0.099	<.0001
≥ 70	-5.802	0.141	<.0001
Marital status			
Married			
Divorce, separation, bereavement	-2.155	0.113	<.0001
Unmarried	-0.817	0.094	<.0001
Education			
Less than middle school	Ref	-	-
High or middle school graduate	3.161	0.095	<.0001
College graduate	3.398	0.102	<.0001
Household income			
Q1(Low)	Ref	-	-
Q2	2.24	0.097	<.0001
Q3	2.438	0.095	<.0001
Q4(High)	2.341	0.094	<.0001
Economic activity			
No	Ref	-	-
Yes	2.544	0.068	<.0001
Household type			
First generation	Ref	-	-
Second generation	-0.563	0.069	<.0001
Third generation	-0.568	0.101	<.0001
Chronic disease			
0	Ref	-	-
1	-1.434	0.073	<.0001
≥ 2	-5.589	0.115	<.0001
Perceived health status			
Poor	Ref	-	-
Good	3.24	0.046	<.0001

*All variables were simultaneously adjusted

Table 3. Coefficients of EQ-5D Score According to Subgroup

| | Part of a cancer family | | | |
| | No | Yes | | |
	β	β*	S.E	p-value
Sex				
Men	Ref	0.149	0.215	0.4877
Women	Ref	-0.698	0.289	0.0158
Economic activity				
No	Ref	-0.292	0.349	0.4041
Yes	Ref	-0.422	0.185	0.0225

*Adjusted for age, education, marital status, household income, household type, chronic disease, and perceived health status

β=-0.688, P<0.0001). Those who worked showed more relation with increasing EQ-5D score than those who did not (economic activity: β=2.544, P<0.0001).

Table 3 shows the coefficients of EQ-5D score according to subgroup. The EQ-5D score was associated with being part of a cancer family in women (β=-0.698, P=0.0158) but not men (β=0.149, P=0.4877). The coefficient of the EQ-5D score for members of a cancer family was statistically significant (β=-0.422, P=0.0225) for those who worked but not for those who did not (β=-0.292, P=0.4041).

Discussion

We investigated and compared the HRQOL of cancer families and non-cancer families, with the aim of providing basic data that will facilitate the development of intervention strategies to promote the QOL cancer families. This study was different from previous studies in the sense that the care burden did not limited to the caregiver, but extended to the whole family members.

Overall, the results from this study showed that cancer patients' family members had lower EQ-5D score than non-cancer patients' family members. In Korea, when a person is diagnosed with cancer, the other family members are expected to care for the patient because family ties are closer than in Western countries (Park and Hyun, 2000). In addition, as the patients stay longer at home than in the hospital because of changes in the healthcare environment, the role of the cancer patient's family continues to increase and diversify (Given and Northouse, 2011; Glajchen, 2003). Accordingly, the responsibility for care has been extended to the entire family, not only the caregiver. The increased care burden results in a reduction in QOL (Kitrungrote and Cohen, 2006).

We also observed a difference according to gender. Among males, the EQ-5D scores of cancer families were not significantly lower than those of non-cancer families. However, among females, the scores were significantly lower for cancer families than for non-cancer families. This may be due to several factors. First, females usually fulfill the role of the caregiver due to societal norms (Pavalko and Woodbury, 2000). This may contribute to a greater care burden in females than males (Gallicchio et al., 2002). Second, females generally provide more

caregiving assistance than do males, which may result in a risk of physical or psychological morbidity (Yee and Schulz, 2000).

In addition, we identified differences depending on economic activity. The EQ-5D scores were significantly lower for cancer families than for non-cancer families among those who worked, but not among those who did not. This is because family members maintain employment while they are involved in caregiving and often require an adjustment of their workload (Wadhwa et al., 2013; Zhu et al., 2014). Consistent with previous studies, our findings, considering that the caregiver role of cancer patients' family members is relatively new to the subjects compared to existing roles and providing care to cancer patients demands meeting their multidimensional needs, including treatment monitoring, management of treatment-related symptom, emotional and financial, indicated that the various roles carried out simultaneously by family members are likely to lower their HRQOL (Kim et al., 2006; Girgis et al., 2013).

Caregivers play critical roles in helping patients deal with the effects of cancer and its treatment and regain or maintain their health (Alptekin et al., 2010; Muhamad et al., 2011). Accordingly, it is essential that caregivers be well-prepared, and their well-being should be promoted. For example, initiatives that help cancer families care for their own health, decrease their psychological distress (such as anxiety and depression), maintain family relationships, and receive social support services could improve their HRQOL (Sorensen et al., 2002; Kim and Carver, 2012). Health services and interventions related to this should be developed (Wadhwa et al., 2013).

Our study had several limitations. First, it was a cross-sectional study so no conclusions regarding causality can be reached. That is, we cannot definitively conclude that the lower HRQOL scores in cancer families were in fact due to the presence of cancer patients. Moreover, we had no information regarding the relationship between cancer patients and subjects, the type of cancer, survival time after diagnosis, or cancer stage because the Community Health Survey does not collect such information. Third, selection bias may have occurred against members of families of patients with advanced-stage cancer because they are not likely to respond to survey due to aggravated condition of patients.

Nevertheless, our study had several advantages over previous similar research. We used a nationally representative sample so our results can be generalized. Also, to the best of our knowledge, this is first comparison of HRQOL between cancer and non-cancer families. Previous studies have focused on the mental QOLs of caregivers, and did not measure QOL using the EQ-5D.

In conclusion, there was a significant relationship between HRQOL scores and being a family member of a cancer patient. The lower scores of cancer families indicate that all family members experience detrimental effects due to their roles in caregiving, and thus interventions for entire families might be needed, particularly social assistance. Our results provide reference data for developing a strategy for managing the quality of life of family members of cancer patients.

Acknowledgements

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