

Quality of Life of Caregivers of Cancer Patients: A Cross-Sectional Study

Wardah A. Alghamdi

king Saud bin Abdulaziz university for health sciences

Montaha A. Almatrafi

king Saud bin Abdulaziz university for health sciences

Rimas A. Asiri

king Saud bin Abdulaziz university for health sciences

Lama A. Almuraee

king Saud bin Abdulaziz university for health sciences

Sarah M. Alsharif

king Saud bin Abdulaziz university for health sciences

Faizah M. Makhdoum

king Saud bin Abdulaziz university for health sciences

Malak A. Alghamdi (✉ ghamdima@ksau-hs.edu.sa)

king Saud bin Abdulaziz university for health sciences

Alaa M. Althubaiti

king Saud bin Abdulaziz university for health sciences

Majed A. Alghamdi

King Abdulaziz Medical City, Ministry of National Guard Health Affairs-Western Region (MNGHA-WR)

Research Article

Keywords: Primary caregiver, patient, cancer, oncology, QOL, SF-36

Posted Date: December 7th, 2023

DOI: <https://doi.org/10.21203/rs.3.rs-3692987/v1>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Additional Declarations: No competing interests reported.

Abstract

Background

Cancer is a chronic and serious disease that has a wide range of effects on patients. Some of these effects extend to family members and primary caregivers (PCs), thereby impacting their quality of life (QOL). The aim of this study is to evaluate the QOL of PCs of patients with cancer and to investigate the sociodemographic and other factors that impact PCs' QOL.

Methods

This cross-sectional study was carried out at the Princess Noura Oncology Center (PNOC), King Abdulaziz Medical City, Jeddah. A total of 235 PCs were included in this study. A short-form health survey, the SF-36, which includes eight domains, was used to measure the QOL of the patients' caregivers. The relationship between the QOL of PCs and the characteristics of the patients and PCs was examined.

Results

The PCs' QOL was associated with several variables. Results of the multiple regression analysis showed that age, sex of the patient and caregiver, and classification of cancer were independently and significantly associated with QOL. Older, female, and hematological patient's PCs had lower QOL of life; whereas, PCs caring for a female patient experienced a better QOL of life.

Conclusion

These findings highlight the essential aspects of the QOL of Saudi caregivers and their influencing factors. To better understand the implications of these factors, future studies are required to demonstrate the effects of patient- and disease-related factors on PCs' QOL.

1. Introduction

Cancer is a chronic and serious disease that ranks as the second leading cause of death worldwide, accounting for approximately 10 million deaths in 2020 (Ferlay et al. 2021). Unfortunately, the consequences of cancer extend beyond frequent hospital visits and admissions to patients' homes, affecting the quality of life (QOL) of family members and primary caregivers (PCs) (Kim and Given 2008). Patient caregivers may include relatives, partners, or friends who have strong personal relationships with the patient and provide a wide range of support to a person in a difficult or disabling situation (Blum and Sherman 2010). In other words, PCs are those who are expected to be willing to provide care to chronically ill patients, and they could be family members or close friends (Blum and Sherman 2010).

Caring involves both physical and emotional assistance (Schubart et al. 2008; Stajduhar 2013). Although caregiving is meaningful and firmly associated with human nature, it can significantly reduce the QOL of PCs (Kim and Given 2008). Several studies have shown that PCs may encounter the same or even greater levels of mental distress than cancer patients (Hagedoorn et al. 2008; Northouse et al. 2000). One study found that the prevalence of anxiety and depression among caregivers of cancer patients was remarkably high, and their QOL was low (Kilic and Oz 2019). In addition, the effect of cancer on PCs is not specific to disease progression itself (Kilic and Oz 2019). Although cancer is the major cause of reduced QOL, several other factors may further deteriorate QOL (Geng et al. 2018). Such factors include the relationships and interactions between patients and PC, economic status, caregivers' social and psychological characteristics, caregivers' health, and caregiving duration (Geng et al. 2018). These results indicate that research following a comprehensive examination of the several psychological and social aspects of caregivers of patients with cancer is crucial, both to evaluate and enhance the effectiveness of caregiving and the QOL of PCs.

As most of QOF research regarding PCs of cancer patients was conducted in Western populations (Chambers et al. 2013), little is known about PCs' QOL of cancer patients in Saudi Arabia. Therefore, this study evaluates the QOL of PCs of cancer patients in Jeddah, Saudi Arabia.

2. Materials and methods

2.1 Research setting

This cross-sectional study was employed at the Princess Noura Oncology Center (PNOC). It is part of King Abdulaziz Medical City, a tertiary care hospital in Jeddah and the largest urban hospital in Makkah Province in the western part of Saudi Arabia.

2.2 Sample

Given the average of 600 new cancer cases diagnosed every year at PNOC, the minimum required sample size was 235 using 95% confidence interval.

All participants were PCs for cancer patients who visited the center between January 1, 2022, and August 30, 2022. The interviews were conducted with PCs aged 18 years or older. A PC was defined as a person who takes the greatest responsibility for care and spends most of the time required to care for the patient without obtaining financial compensation. Only the PCs of patients who were diagnosed with cancer for six months or more were included to avoid the potential initial stress associated with the diagnosis that might affect their QOL. The PCs of patients with solid and hematological malignancies were of interest at any stage and at any point of treatment in the oncology outpatient department.

2.3 Sampling technique

Convenience sampling was performed. Patients were stratified into solid and hematological malignancies. Under each category, clinics were selected weekly, and all PCs attending clinics with

patients (one PC per patient) were included if they met the inclusion criteria.

2.4 Data collection

Data were collected via an interview-based questionnaire (face-to-face) by trained medical students under the supervision of an oncologist. The procedure was performed at the PNOC daily oncology clinics for adults and pediatric patients, and chemotherapy outpatient administration rooms. First, the interviewers selected patients from the hospital patient electronic record system (BestCare) based on the diagnosis and time since diagnosis that met our eligibility criteria. At each location, potential participants were approached and asked to participate by a medical student. To preserve confidentiality and privacy, the interviews were conducted in a private room in the hospital, and only one student approached the candidate PCs. Data collection was about 10–15 minutes per individual. During the relevant period, all questions were asked to the participants, and responses were entered into the data collection sheet after ensuring that the participants were able to comprehend the questions. Disease-related questions, treatment details, and demographics of the patients were extracted directly from patients' electronic records.

2.5 Measurements

To measure the QOL of the patients' caregivers, a short-form health survey, the SF-36, was used (Kim and Given 2008). It is composed of 36 items that measure eight domains of health being: *physical functioning* (ten items) that deals with limitations in daily activities due to health issues (e.g., dressing), *physical role limitations* (four items) concerned with limitation in usual role activities (e.g., work) because of physical health issues; *bodily pain* (two items) describing bodily pain intensity; *general health perceptions* (five items) which require subjective evaluation of general health status in comparison to others; *energy/vitality* (four items) for any sign of loss of energy or fatigue; *social functioning* (two items) for limitation in social activities due to physical or emotional problems; *emotional role limitations* (three items) concerned with limitations in usual role activities (e.g., work) because of emotional problems; and *mental health* (five items) for any psychological distress and overall well-being. The questionnaire also included a single general question: *health change*, concerned with perceived change in health over a one-year period and was not included in the scoring process. The eight subscale scores were calculated as shown in Table 3 using SF-36 scoring manual. No single measure of health-related QOL was provided in the manual, and a very low proportion of studies (1.8%) attempted calculating SF-36 total score (Lins and Carvalho 2016). As stated by Dorman et al. (1999), much clinical information about exact responses can be lost as the total score can be obtained from various answers. These eight domains can be combined to generate two summary components: a physical component summary and a mental component summary. Nevertheless, literature evidence suggests that SF-36 is a multidimensional model. Hobart et al. (2002) reported that the usage of a two-dimensional model would guarantee the loss of a substantial amount of information, and the scale-to-component correlation might be disease-specific when stroke patient summary measures are compared with those of the general US population. Both the English and Arabic versions of the SF-36 were used. The Arabic language questionnaire was used during the

interviews and was shown to be reliable and similar to the original English version (Ware et al. 1992; Al Abdulmohsin et al. 1997).

Questions extracted from Health Electronic Record (BestCare) consisted of the patients' sociodemographic information (age, sex, nationality, date of diagnosis, and current performance status). The current performance status of the patient, as measured by the Eastern Cooperative Oncology Group (ECOG), is a five-point scale used by physicians to assess the progression of the disease and independence of patients in their daily activities, and to determine suitable treatment and effective prognosis for patients (Abbasi et al. 2020). Other information taken from BestCare included the characteristics of the disease (classification of cancer, type of cancer, stage, and status of disease) and treatment (intent of treatment, presence of active treatment, and type of treatment). In cases where patients were not on any active treatments or were lost to follow-up, researchers collected treatments within the last six months; if there were none, the last treatment was recorded.

Questions involving PC information were asked directly during interviews with the data collectors. These questions included the PC's (age, sex, ethnicity, marital status, education, level of education, relationship with the patient, understanding of disease, and duration and intensity of caregiving). Concomitant intensity was measured as the overall duration of care (months/years) and average time spent providing care per day (hours). Finally, the data were entered into Microsoft Excel.

Data analysis

Statistical analysis was done using JMP® pro, Version < 15.2>. SAS Institute Inc., Cary, NC (1989–2023) for Mac software. Eight QOL scales were determined using the standard SF-36. Coding, re-calibrating, totaling, and translating from 0 to 100 were done on all raw scores, with higher scores indicating better QOL. The distributions of the continuous variables were assessed for normality assumptions using Shapiro-Wilk test, and these variables are expressed as mean (\pm standard deviation), and median (inter-quartile range). Categorical variables are expressed as frequencies and percentages. First, we examined bivariate associations between SF-36 measures and the characteristics of caregivers (age, sex, marital status, employment, relationship with patient, educational level, and understanding of disease), commitment intensity (total amount of time in months and hours spent in caregiving), and the characteristics of patients (age, sex, type of cancer, classification of cancer, stage of cancer, status of disease, intent of treatment, and treatment type). The Mann-Whitney *U* test was used as stated by the distribution of the data. Spearman's correlation coefficients (ρ) between the SF-36 components and age were computed. The Kruskal-Wallis test was utilized in comparisons of more than two groups. In our study, among the SF-36 components, data from most subscales were not normally distributed; for consistency, all data from the SF-36 were analyzed using non-parametric methods. Multiple linear regression was done to determine the variables that were significantly and independently associated with the QOL domains. Statistical significance was set at $p < 0.05$.

3. Results

3.1 Demographic characteristics

In total, 235 PCs were included in this study. Table 1 shows the demographic characteristics of the PCs. In this cross-sectional study, female caregivers predominated (60%). The mean age of the PCs was 37.34. Of the 235 participants, 95% of the PCs were patient relatives. PCs were patients' children in 42%, parents in 35%, and spouses, colleagues, or friends in 15% of the PCs. Approximately 62% of PCs were married, 30% were single, and 7% were divorced. When asked how well they were informed about the disease, 70% were informed and 30% were partially informed. Additional demographic characteristics of the participants are summarized in Table 1.

Table 1
Caregiver characteristics.

Characteristic	Count	Percent
Age (mean \pm SD) year	37.34 \pm 10.76	
Sex:	141	60%
Female	94	40%
Male		
Marital status:	147	62.6%
Married	70	30%
Single	17	7%
Divorced	1	0.4%
Widowed		
Working status:	99	42%
Employed	119	51%
Unemployed	17	7%
Retired		
Patient relationship:	23	10%
Husband\wife	82	35%
Father\mother	19	8%
Brother\sister	100	42%
Son\daughter	11	5%
Other		
Educational level:	14	6%
Primary school or less	78	33%
Middle or high school	143	61%
University or above		
Informed about the disease:	71	30%
Partly informed	164	70%
Well-informed		
Duration of caregiving (mean \pm SD) months	37.07 \pm 41.01	

Characteristic	Count	Percent
Time per day spent in caregiving (mean \pm SD) hours	11.20 \pm 9.17	

Patient characteristics are presented in Table 2. Of the 235 patients, more than half were female (64%). The mean patient age was 42.9 years. In regard to disease status, 36% of patients were in remission, 34% had progressive disease, while few of them were considered cured (6%). The majority of the patients had solid tumors (67%); 21.7% of them had breast cancer, 7.7% had colon cancer and 3.4% had lung cancer. On the other hand, leukemia accounts for most of the hematological tumors (26.4%). Overall, 68% of the patients had advanced stage of malignancy. Most patients received systemic therapy (72%) or combined therapy (5%). The intention of treatment was curative in 65% and palliative in 35% of the patients.

Table 2
Patient characteristics.

Characteristics	Count	Percent
Age (mean \pm SD) year	42.9 \pm 25.57	
Sex:	150	64%
Female	85	36%
Male		
Type of cancer:	51	21.7%
Breast cancer	18	7.7%
Colon cancer	8	3.4%
Lung cancer	3	1.3%
Prostate cancer	62	26.4%
Leukemia	1	0.3%
Lymphoma	80	34%
Other		
Classification of cancer:	158	67%
Solid	77	33%
Hematological		
Stage of cancer:	67	32%
Early	140	68%
Advanced		
Status of disease:	14	6%
Cured	84	36%
Stable\in remission	38	16%
Responding disease	79	34%
Progressive disease	20	8%
Recurrent disease		
Intent of treatment:	153	65%
Curative	82	35%
Palliative		

Characteristics	Count	Percent
Active treatment:	170	72%
Systemic therapy	2	0.8%
Radiation therapy	6	3%
Surgery	12	5%
Combined therapy	45	19%
None		
Previous treatment (6 months or more):	17	37.8%
Systemic therapy	7	15.5%
Surgery	18	40%
Combined therapy	3	6.7%
None		

3.2 Quality of life of caregivers

Table 3 shows the collective scores for each of the eight domains that encapsulate the QOL of PCs. From lowest to highest, energy/fatigue scored a median of 55 (max = 100, min = 0), followed by role functioning/emotional at 66.66 (max = 100, min = 0), emotional well-being at 72 (max = 100, min = 0), role functioning/physical at 75 (max = 100, min = 0), general health at 80 (max = 100, min = 0), social functioning at 87.5 (max = 100, min = 0), and pain at 90 (max = 100, min = 0). The highest score among all eight domains was for physical functioning at 100 (max = 100, min = 5).

Table 3
Reliability, central tendency, and variability of scales in cancer caregivers.

Scales	Alpha	Min	Median	Max
Physical functioning	0.83	5	100	100
Role functioning/physical	0.86	0	75	100
Role functioning/emotional	0.81	0	66.66	100
Energy/fatigue	0.67	0	55	100
Emotional well-being	0.76	0	72	100
Social functioning	0.88	0	87.5	100
Pain	0.76	0	90	100
General health	0.6	0	80	100

3.3 Patients' and primary caregivers' characteristics associated with QOL

Table 4 shows the PCs' demographics associated with the QOL domains. Female PCs scored lower than males in physical functioning ($p = 0.010$), social functioning ($p = 0.001$), role limitation due to physical health ($p = 0.0001$), role limitation due to emotional health ($p = 0.005$), emotional well-being ($p < 0.0001$), and pain ($p < 0.0001$). While exploring the relationship of patients to PCs, parents documented a lower score in energy and fatigue ($p = 0.121$) compared to siblings, spouses, offspring, and others. Regarding marital status, married PCs experienced significantly worse QOL than nonmarried PCs ($p = 0.044$). PCs' employment status showed a statistical difference in physical functioning ($p = 0.571$), role limitation due to emotional health ($p = 0.014$), and emotional well-being ($p = 0.001$); unemployed PCs scored lower on the QOL scale than employed and retired PCs.

Table 5 shows patient- and disease-related demographics and their associations with the QOL domains. The sex of the patient showed a statistically significant difference in social functioning ($p = 0.012$). PCs caring for male patients experienced better QOL than those caring for female patients. Classification of cancer showed statistically significant differences in five domains: physical functioning, general health, role limitation due to emotional health, pain, and social functioning ($p = 0.004$), ($p = 0.573$), ($p = 0.044$), ($p = 0.039$), ($p = 0.003$), respectively; in other words, PCs of hematological patients scored lower in five aspects than PCs of patients with solid tumors.

A linear correlation using Spearman's rho correlation coefficient was used to test the association between QOL and the duration of caregiving in months, time per day spent in caregiving, age of PCs, and age of

the patient. Regarding PC age, we found a weak positive correlation between PC age and emotional well-being ($r = 0.14$, $p = 0.028$) and a weak negative association between age and pain ($\rho = -0.13$, $p = 0.045$). As for the age of the patient, it was correlated with two aspects: emotional well-being ($\rho = 0.13$, $p = 0.041$) and social functioning ($\rho = 0.27$, $p < 0.0001$). In other words, the older the patients, the better the QOL of the PCs. The months of caregiving showed a correlation with two aspects: role limitations due to physical health ($\rho = 0.13$, $p = 0.040$) and social functioning ($\rho = 0.19$, $p = 0.004$). In terms of hours per day of caregiving, a correlation was found with role limitations due to physical health ($\rho = -0.15$, $p = 0.019$), role limitations due to emotional health ($\rho = -0.17$, $p = 0.011$), social functioning ($\rho = -0.37$, $p < 0.0001$), pain ($\rho = -0.14$, $p = 0.029$), emotional well-being ($\rho = -0.23$, $p = 0.0005$), and energy and fatigue ($\rho = -0.15$, $p = 0.025$).

Table 6
Multiple linear regression analysis for independent variables associated with quality of life.

Dependent variable	Independent variables	Unstandardized coefficient (B)	t	P-value
Physical functioning	Classification of cancer [hematologic]	-3.23	-2.97	0.003
Social functioning	Caregiver sex [female]	-6.81	-2.91	0.0039
	Patients sex [female]	5.53	2.30	0.022
	Hours caregiving	-1.04	-4.17	< 0.0001
Role limitations due to physical health	Caregiver sex [female]	-9.18	-2.95	0.003
Energy and fatigue	Caregiver sex [female]	-6.47	-4.06	< 0.0001
Emotional well being	Caregiver sex [female]	-4.12	-2.28	0.023
	Hours caregiving	-0.50	-3.03	0.003
Pain	Caregiver sex [female]	-6.27	-3.50	0.0006
	Caregiver age	-0.36	-2.26	0.024

Significant results are presented.

The results of the regression analyses shown in Table 6 indicated that the classification of cancer was independently and significantly associated with physical functioning ($B = -3.23$, $p = 0.003$); hematological cancer patients showed a negative association when compared to the reference group solid. Female PCs also showed a negative association with social functioning ($B = -6.81$, $p = 0.0039$), role limitation due to physical health ($B = -9.81$, $p = 0.003$), energy and fatigue ($B = -6.47$, $p < 0.0001$), emotional well-being

($B=-4.12$, $p = 0.023$) and pain ($B=-6.27$, $p = 0.0006$) compared to male PCs. Patient sex was also a predictor of social functioning ($B = 5.53$, $p = 0.022$), as female patients showed a positive association with social functioning compared to their counterpart male patients. Caregiving hours were negatively associated with social functioning ($B=-1.04$, $p < 0.0001$) and emotional well-being ($B=-0.50$, $p = 0.003$). PCs' age was independently and significantly associated with pain ($B= -0.36$, $p = 0.024$); the older the PC the more pain they experience.

4. Discussion

To the best of our knowledge, only a few local studies have examined the factors affecting the QOL of PCs in Saudi Arabia (Almutairi et al. 2017). The purpose of this study was to describe the demographics, disease factors, and their relationship with the QOL of caregivers of cancer patients. Among all demographic characteristics, sex of PC remains the most studied factor in regard to PC's QOL in literature with consistent findings of poorer QOL and higher levels of psychological distress in female PCs than males (Kim and Given 2008; Decadt et al. 2021). When comparing the eight domains of the QOL of PCs to their demographics in our study, sex was found to be the only demographic characteristic that was statistically different in all domains except for general health. Female caregivers performed poorly in every QOL aspect as opposed to their male counterparts, who scored much lower median rates. Our findings are in line with those of Almutairi et al.'s (2017) study, conducted in Riyadh, in terms of significant results ($p < 0.05$) in the energy/fatigue, role limitation due to emotional health, social functioning, and pain domains. Moreover, it highlights the significance of physical components, physical functioning, and role limitations due to physical health, along with emotional well-being domains. This may be explained by the existing literature reporting sex differences in QOL due to women's traditional sex roles in society (Matthews 2003). This comes to light in certain cultures, especially in middle eastern cultures, where women hold great familial responsibility. Thus, they are expected to provide the necessary care and devotion to their families especially when they are ill and in need as reported by similar studies in Iran, Turkey, and Singapore (Kilic and Oz 2019; Lim et al. 2017; Wiener et al. 2016), and Saudi Arabia is not an exception. Women also showed high willingness to disclose their emotional distress and concerns (Decadt et al. 2021). This may have contributed to their low median results in the emotional well-being domain in our study.

We found a statistically significant difference in the QOL scores concerning social functioning among PCs who were parents. Our results are consistent with those of other studies that have reported poorer social life during caregiving. It was explained that PCs had less time to spend with their families and relatives, and they did not have the energy and time to meet their requirements (Osse et al. 2006; Uğur and Z 2012). In contrast, other studies found that during the journey of caring for their patients, family rapport was reinforced, and they were more engaged together, indicating that the caregiving process had some positive effects on social relationships (Kilic and Oz 2019; Yu et al. 2017; Li and Loke 2013). It is commonly acknowledged that the relationship between PCs and the patients for whom they care greatly impacts the QOL of PCs. Furthermore, our study found that offspring of patients with cancer had better social functioning. According to other studies, this was because they had less familial and monetary

responsibility than their parents and spouses, who were subjected to tremendous strain and had more obligations to care for (Almutairi et al. 2017).

This study also showed that non-married caregivers had a better QOL than married caregivers. However, other studies have found that married caregivers had better QOL (Abbasi et al. 2020; Lee et al. 2015). Abbasi et al. (2020) explained that single caregivers pursue more leisure activities and are exposed to more stressors than married caregivers. The inconsistency in the results could be because the married and non-married participants were asked based on demographic information, and the question was not about the PC's perception of social support. Wiener et al. (2016) further explained the dynamics of this idea, in which they compared single vs. non-single parents' QOL based on the parents' own self-reports of feeling alone in caring for their child.

Regarding employment status, we found that PCs respondents who were working or retired scored better on role limitations due to physical, emotional, and overall emotional health than those who were unemployed. These findings are consistent with those of other studies. Kilic and Oz (2019) reported that unemployed caregivers scored lower on the QOL than those who were employed or retired. Although unemployed caregivers have less responsibility and more time to deliver care to their patients, their inability to provide financial assistance can lead to feelings of self-inadequacy and uselessness, which may negatively affect them.

Regarding the age of PCs, this study found a weak positive correlation between the age of PCs and emotional well-being, and a very weak negative association with age and pain. In other words, the older the PC, the better their emotional well-being and the higher their level of pain. (Holgín et al. 2021) explained that aged individuals' coping styles tend toward resignation and the development of resilience factors, as they have been exposed to decades of armed conflict (Gaviria et al. 2016). Higher pain scores can be attributed to the physiological effects of aging on health. Further research is required to explain this relationship.

Our study found a positive correlation between the QOL of PCs and patient age in two domains of the SF-36: emotional well-being and social functioning. In other words, the higher the patient's age, the better the QOL of the caregivers. It is noteworthy to mention that in this study, 78% of patients aged 14 and below had leukemia as their diagnosis. Our study was in line with the findings of (Yu et al. 2017), who found that young patient age (< 15 years) was associated with a lower QOL of PCs in the physical, psychological, and environmental domains. Their findings were also attributed to the fact that 64% of acute lymphoblastic leukemia patients were younger than 15 (Yu et al. 2017). In contrast, another study found that younger cancer patients had a greater QOL, which consequently produced an overall better QOL in PCs (Shahi et al. 2014).

These findings led us to another significant finding of this study. A comparison was made between the QOL of PCs and the classification of cancer patients, and significant results were observed for five aspects of the SF-36. All five aspects showed that PCs of hematological subtype patients had a lower QOL. A study conducted in China, where QOL of caregivers of patients with leukemia was compared with

that of the general population, found that caregivers of patients with leukemia had low QOL scores in all domains (Yu et al. 2017). Another study conducted in Japan found that mothers caring for patients with leukemia had lower scores in all eight domains of the SF-36 than mothers caring for children without leukemia (Yamazaki et al. 2005). One explanation can be attributed to the duration of caregiving per day in hours in our study, in which the PC of hematological patients spent an average of 14.21 hours in caring, while solid patient caregivers spent an average of 9 hours. It is also noteworthy that, in our study, the majority of hematological patients' caregivers were parents, while for solid cancers, the majority were sons or daughters. For PCs of children with chronic diseases, the presence of the disease itself can be a greater stressor in care than in healthy children. Although the therapeutic outcome of leukemia has improved considerably, the long duration and course of treatment, complications, and high medical costs continue to burden many parents (Curran and Stock 2015).

5. Limitations

Our study used an interview-based questionnaire for the QOL of cancer patients' PCs at PNCO, Jeddah. This practical assessment provided definite data and allowed us to limit confusion regarding the questions, because they were face-to-face. As a convenience sampling approach was used, the results cannot be applied to the population of Saudi Arabia (Althubaiti 2023). Therefore, researchers from other tertiary centers in Saudi Arabia are encouraged to conduct further studies. Our study included specific inclusion criteria with a diagnosis of six months and more. Meaning, we avoided the stressful period, the first six months after receiving the cancer diagnosis. In addition, we could not establish causality because of the cross-sectional study design and convenience sampling. This might limit the scope of the study, and thus, the results. Despite our best efforts, we could not include performance status of patients (ECOG) due to its limited documentation in our center. Although we collected data on the type of treatment and duration of caregiving, we could not determine an association between these variables and PC's QOL.

6. Conclusions

The results showed that particular attention should be paid to female caregivers and caregivers of patients with hematological malignancies. This study further emphasizes that female caregivers experience lower QOL in many domains. Even though sex has been well studied in the literature, the cause in many studies was solely attributed to the traditional role of females as PCs. Likewise, multiple domains for patients with hematological cancers were low and certain characteristics of both patients and their PCs were attributed for that effect. Interestingly, we found that PCs of female patients had better QOL than PCs of male patients. Our results are promising; however, further studies are needed to highlight the association between more patient-related and disease-related factors that may provide an in-depth understanding of this topic.

Declarations

Funding: The authors declare that no funds, grants, or other support were received during the preparation of this manuscript.

Competing Interests: None to declare

Author Contributions: Each author participated in writing the proposal, data collection, data analysis, manuscript preparation, and approved its content.

Data Availability: Data is available with the corresponding author and can be provided amid reasonable requests.

Ethics Approval

The approval of the Institutional Review Board (IRB) committee of King Abdullah International Medical Research Center was obtained for this study (IRB/0502/22). The PCs were verbally informed about the study and their participation was optional and voluntary.

Consent to participate: Primary caregivers were verbally informed about the study, and their participation was entirely optional and voluntary.

Consent to publish: None to declare.

References

1. Abbasi A, Mirhosseini S, Basirinezhad MH, Ebrahimi H (2020) Relationship between caring burden and quality of life in caregivers of cancer patients in Iran. *Support Care Cancer* 28(9):4123–4129. <https://doi.org/10.1007/s00520-019-05240-y>
2. Adult Oncology Department (KAMC-WR) [Internet]. Princess Noorah Oncology Center. [cited 2022 Oct 3]. Available from: <https://ngha.med.sa/English/MedicalCities/Jeddah/MedDepartments/PNOC/Pages/default.aspx>
3. Al Abdulmohsin SA CS, Draugalis JLR, Hays RD. Transl Rand 36-item health survey 1.0 (aka SF-36) into Arabic 1997 [Available from: <https://www.rand.org/pubs/papers/P7995.html>].
4. Almutairi KM, Alodhayani AA, Alonazi WB, Vinluan JM (2017) Assessment of health-related quality of life among caregivers of patients with cancer diagnosis: A cross-sectional study in Saudi Arabia. *J Relig Health* 56(1):226–237. <https://doi.org/10.1007/s10943-016-0261-4>
5. Althubaiti A (2023) Sample size determination: A practical guide for health researchers. *J Gen Fam Med* 24(2):72–78. <https://doi.org/10.1002/jgf2.600>
6. Blum K, Sherman DW (2010) Understanding the experience of caregivers: a focus on transitions. *Semin Oncol Nurs* 26(4):243–258. <https://doi.org/10.1016/j.soncn.2010.08.005>
7. Chambers SK, Hyde MK, Au AM, Ip D, Shum D, Dunn J (2013) A systematic review of psycho-oncology research in Chinese populations: emerging trends. *Eur J Cancer Care (Engl)* 22(6):824–831.

<https://doi.org/10.1111/ecc.12087>

8. Curran E, Stock W (2015) How I treat acute lymphoblastic leukemia in older adolescents and young adults. *Blood* 125(24):3702–3710. <https://doi.org/10.1182/blood-2014-11-551481>
9. Decadt I, Laenen A, Celus J, Geyskens S, Vansteenlandt H, Coolbrandt A (2021) Caregiver distress and quality of life in primary caregivers of oncology patients in active treatment and follow-up. *Eur J Cancer Care (Engl)* 30(3):e13399. <https://doi.org/10.1111/ecc.13399>
10. Dorman PJ, Dennis M, Sandercock P (1999) How do scores on the EuroQol relate to scores on the SF-36 after stroke? *Stroke* 30(10):2146–2151. <https://doi.org/10.1161/01.str.30.10.2146>
11. Ferlay J, Colombet M, Soerjomataram I, Parkin DM, Piñeros M, Znaor A, Bray F (2021) Cancer statistics for the year 2020: an overview. *Int J Cancer*. <https://doi.org/10.1002/ijc.33588>
12. Gaviria SL, Alarcón RD, Espinola M, Restrepo D, Lotero J, Berbesi DY, et al (2016) Socio-demographic patterns of posttraumatic stress disorder in Medellín, Colombia and the context of lifetime trauma exposure. *Disaster Health* 3(4):139–150. <https://doi.org/10.1080/21665044.2016.1263086>
13. Geng HM, Chuang DM, Yang F, Yang Y, Liu WM, Liu LH, Tian HM (2018) Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. *Med (Baltim)* 97(39):e11863. <https://doi.org/10.1097/MD.00000000000011863>
14. Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC (2008) Distress in couples coping with cancer: a meta-analysis and critical review of role and sex effects. *Psychol Bull* 134(1):1–30. <https://doi.org/10.1037/0033-2909.134.1.1>
15. Hobart JC, Williams LS, Moran K, Thompson AJ (2002) Quality of life measurement after stroke: uses and abuses of the SF-36. *Stroke* 33(5):1348–1356. <https://doi.org/10.1161/01.str.0000015030.59594.b3>
16. Holgín EA, Arias-Rojas M, Moreno SC (2021) Quality of life of family caregivers of people with cancer in palliative care. *Rev Esc Enferm USP* 55:e03740. <https://doi.org/10.1590/S1980-220X2020015103740>
17. Kilic ST, Oz F (2019) Family caregivers' involvement in caring with cancer and their quality of life. *Asian Pac J Cancer Prev* 20(6):1735–1741. <https://doi.org/10.31557/APJCP.2019.20.6.1735>
18. Kim Y, Given BA (2008) Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. *Cancer* 112(11) Suppl:2556–2568. <https://doi.org/10.1002/cncr.23449>
19. Lee HJ, Park EC, Kim SJ, Lee SG (2015) Quality of life of family members living with cancer patients. *Asian Pac J Cancer Prev* 16(16):6913–6917. <https://doi.org/10.7314/apjcp.2015.16.16.6913>
20. Li Q, Loke AY (2013) The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psycho-Oncology* 22(11):2399–2407. <https://doi.org/10.1002/pon.3311>
21. Lim HA, Tan JY, Chua J, Yoong RK, Lim SE, Kua EH, Mahendran R (2017) Quality of life of family caregivers of cancer patients in Singapore and globally. *Singapore Med J* 58(5):258–261. <https://doi.org/10.11622/smedj.2016083>

22. Lins L, Carvalho FM (2016) SF-36 total score as a single measure of health-related quality of life: scoping review. *SAGE Open Med* 4:2050312116671725. <https://doi.org/10.1177/2050312116671725>
23. Matthews BA (2003) Role and sex differences in cancer-related distress: a comparison of survivor and caregiver self-reports. *Oncol Nurs Forum* 30(3):493–499. <https://doi.org/10.1188/03.ONF.493-499>
24. Northouse LL, Mood D, Templin T, Mellon S, George T (2000) Couples' patterns of adjustment to colon cancer. *Soc Sci Med* 50(2):271–284. [https://doi.org/10.1016/s0277-9536\(99\)00281-6](https://doi.org/10.1016/s0277-9536(99)00281-6)
25. Osse BH, Vernooij-Dassen MJ, Schadé E, Grol RP (2006) Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nurs* 29(5):378–388; quiz 89–90. <https://doi.org/10.1097/00002820-200609000-00005>
26. Schubart JR, Kinzie MB, Farace E (2008) Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol* 10(1):61–72. <https://doi.org/10.1215/15228517-2007-040>
27. Shahi V, Lapid MI, Kung S, Atherton PJ, Sloan JA, Clark MM, Rummans TA (2014) Do age and quality of life of patients with cancer influence quality of life of the caregiver? *J Geriatr Oncol* 5(3):331–336. <https://doi.org/10.1016/j.jgo.2014.03.003>
28. Stajduhar KI (2013) Burdens of family caregiving at the end of life. *Clin Invest Med* 36(3):E121–E126. <https://doi.org/10.25011/cim.v36i3.19722>
29. Uğur ÖF, Z (2012) The effect of planned education applied to caregivers of cancer patients on caregiver burdens
30. Ware JE, Sherbourne CD' (1992) The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 30(6):473–483. <https://doi.org/10.1097/00005650-199206000-00002>
31. Wiener L, Viola A, Kearney J, Mullins LL, Sherman-Bien S, Zadeh S, et al (2016) Impact of caregiving for a child with cancer on parental health behaviors, relationship quality, and spiritual faith: do lone parents fare worse? *J Pediatr Oncol Nurs* 33(5):378–386. <https://doi.org/10.1177/1043454215616610>
32. Yamazaki S, Sokejima S, Mizoue T, Eboshida A, Fukuhara S (2005) Health-related quality of life of mothers of children with leukemia in Japan. *Qual Life Res* 14(4):1079–1085. <https://doi.org/10.1007/s11136-004-3288-z>
33. Yu H, Li L, Liu C, Huang W, Zhou J, Fu W, et al (2017) Factors associated with the quality of life of family caregivers for leukemia patients in China. *Health Qual Life Outcomes* 15(1):55. <https://doi.org/10.1186/s12955-017-0628-6>

Tables

Tables 4 and 5 are available in the Supplementary Files section.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Table45.docx](#)