



# Quality of life and related factors in caregivers of children with cancer in Iran

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## Abstract

**Purpose** The aim of this study was to determine the quality of life and its related factors in the caregivers of children with cancer.

**Methods** This cross-sectional study assessed the quality of life of 270 caregivers of children with cancer in Iran. Data collection tools were a personal information form and the Caregiver Quality of Life Index-Cancer. Data were analyzed by SPSS-18 software using descriptive and inferential statistics (independent *t*-test, analysis of variance, and linear regression model).

**Results** The mean score of quality of life was  $78.3 \pm 1.6$  out of 140. Variables that were significantly associated with quality of life included age ( $p = .031$ ), gender ( $p = .021$ ), education ( $p = .048$ ), occupation ( $p = .011$ ), economic status ( $p = .038$ ), average caring time ( $p = .021$ ), and age of the child ( $p = .011$ ).

**Conclusion** The caregivers of children with cancer did not have a good quality of life. Healthcare providers need to provide comprehensive educational, emotional, social, and economic support to the caregivers of patients with cancer.

**Keywords** Quality of life · Caregivers · Child · Cancer

## Introduction

In recent years, the prevalence of cancer in children has increased so that it is estimated that 13.7 million children worldwide will develop cancer between 2020 and 2050 [1]. In addition to the patient, the diagnosis of cancer affects the

family members, especially parents as primary caregivers [2]. Caring for a patient with cancer poses many challenges to caregivers in terms of physical and mental health, family and social relationships, daily activities, and economic status [3]. Evidence shows that the family members of the sick child, as primary caregivers, are concerned about the premature death of the child and feel guilty, angry, and frustrated [4]. The length of illness and treatment, frequent hospital admissions, medical expenses, and poor mental health are some of the stressors that challenge the patient's family and can reduce the quality of life of caregivers [3, 5].

Quality of life is an important health outcome and a state of complete physical, mental, social, and spiritual health that is affected by various sociodemographic variables [6, 7]. There are many definitions for the quality of life, and there is no consensus on this. Yet, the World Health Organization defines quality of life as people's perception of their position in life in the context of the culture and value systems in which they live [3, 5–8]. Quality of life is a multifaceted concept and is equivalent to the feeling of general satisfaction with different aspects of life [6–8]. Quality of life is strongly influenced by time and place, and its components and factors vary according to time period and geographical location [3, 5–8]. Different aspects of quality of life are also

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not equally important to different people and differ in various situations [3, 5–8].

There are several factors that affect the quality of life of caregivers of children with cancer, including age, sex, education, occupation, income, and the severity of the disease [7, 8]. In this regard, the results of a study in Indonesia (2020) showed that 58.8% of caregivers of children with cancer had a poor quality of life and most of them were male and had low-income and a low level of education [7]. In another study in Iran (2011), the caregivers of children with cancer had poor quality of life in all domains [9]. In a study (2015) in Sri Lanka, about half of caregivers of children with cancer had poor quality of life [10]. The results of a qualitative study in Iran (2017) showed that the caregivers of patients with cancer face several challenges such as feeling of instability, anxiety, helplessness, confusion, and stress [4].

Decreased quality of life of parents may reduce the quality of care as well as the quality of life of the patient. Parents who are under the care burden and experience a low quality of life may not be able to take good care of their child [3]. Therefore, to improve the quality of care for children with cancer, it is necessary to pay attention to the quality of life of parents as primary caregivers [7]. The first step in helping caregivers with diminished quality of life is to identify them, which plays an important role in promoting their health and improving the quality of care provided to the patient [7, 11]. Due to the limited number of studies that have examined the quality of life and its related factors in the caregivers of children with cancer in Iran, this study was performed to evaluate the quality of life and its associated factors in the caregivers of children with cancer.

## Materials and methods

### Study design

This cross-sectional descriptive-analytical study was carried out based on the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [12]. In cross-sectional studies, due to the simultaneous measurement of exposure and outcome variables, it is not possible to determine the cause-and-effect relationships between the study variables [13].

### Sample and sampling method

The study population comprised all caregivers of children with cancer hospitalized in Mohammad Kermanshahi Hospital. This hospital is the main center of pediatric cancer in western Iran, which is located in the city of Kermanshah - a western province of Iran. Based on the study of Sajjadi et al. (2011) on the quality of life of caregivers [9], the sample size

was estimated to be 170 people, with a standard deviation of 1, an error of 5%, and accuracy of 15. Due to the multiplicity of independent variables, 100 participants were added to this number and finally 270 participants were recruited by convenience sampling method. The inclusion criteria were consent to participate in the study and having a child with cancer.

### Study instruments

Data collection tools were a personal information form and the Caregiver Quality of Life Index-Cancer (CQOLC). The data collection form consisted of two parts. The first part was dedicated to the caregivers' sociodemographic information, including age, sex, occupation, income, education, number of care hours, marital status, and type of relationship with the patient. The second part was about the patient's demographic information, including age, sex, type of cancer, and duration of cancer diagnosis.

The CQOLC was developed by Weitzner et al. (1997) [14] and its internal consistency was confirmed using Cronbach's  $\alpha$  (0.92) [15]. The Persian version of this tool has been also validated in Iran and has a good reliability index (alpha coefficient of 0.88) [11].

The CQOLC has 35 items rated on a five-point Likert scale: 0 = not at all, 1 = a little bit, 2 = quiet, 3 = much, and 4 = very much. The range of scores is between 0 and 140, and higher scores indicate a better quality of life. The tool has four subscales: mental and emotional burden, lifestyle disruption, positive adjustment, and financial concerns. There is also a phrase related to the individual's interest in care, which is not part of any of these subscales, but is calculated in the total scoring.

### Data collection

This study is part of a larger study. To collect data, the researcher referred to the oncology wards of Mohammad Kermanshahi Hospital and included the caregivers who met the inclusion criteria. Then, the questionnaires were given to the participants and collected after completion. The time required to complete the questionnaires was approximately 15–20 min.

### Statistical analysis

Data were analyzed by SPSS-18 software using descriptive and inferential statistics. For descriptive statistics, mean, standard deviation, and frequency distribution were used. In the inferential statistics section, independent *t*-test, analysis

of variance, and linear regression model were used. The significance level for all tests was less than 0.05.

**Ethical considerations**

The study was approved by the ethics committee of Kerman-shah University of Medical Sciences. The objectives of the study were stated to all participants, and informed written consent was obtained from them. The participants’ data were kept confidential.

**Results**

The mean age of patients was  $1.6 \pm 1.6$  years, and 53.0% ( $n = 142$ ) were male. The mean duration of cancer was  $0.6 \pm 0.7$  months. The mean age of caregivers was  $35.7 \pm 7.0$  years, and most of them were female ( $n = 189$ , 70%), married ( $n = 244$ , 90.4%), parents of children ( $n = 246$ , 91.2%), and had high school diploma ( $n = 98$ , 36.3%). The mean care time was 18 h ( $n = 133$ , 14.3%) (Table 1).

The mean score for quality of life was  $78.3 \pm 1.6$  out of 140. The mean scores of mental/emotional burdens, lifestyle disruption, positive adaptation, and financial concerns were

**Table 2** Frequency distribution of dimensions of the Caregiver Quality of Life Index-Cancer (CQOLC) Scale in caregivers of children with cancer

Dimensions of the Caregiver Quality of Life Index-Cancer (CQOLC) Scale	Score range	Mean $\pm$ SD
Mental/emotional burden	0–56	32.0 $\pm$ 9.4
Lifestyle disruption	0–36	16.3 $\pm$ 6.5
Positive adaptation	0–32	19.6 $\pm$ 3.7
Financial concerns	0–12	7.9 $\pm$ 2.8
Total score of CQOLC Scale	0–140	78.3 $\pm$ 1.6

32 (out of 56), 16.3 (out of 36), 19.6 (out of 32), and 7.9 (out of 12), respectively (Table 2).

The results showed that the quality of life in caregivers over 40 years was higher by an average of 5.5 units than caregivers under 40 years ( $P = 0.031$ ). Female caregivers had a lower quality of life than male caregivers by 5.08 units ( $P = 0.021$ ). With an increase in the level of education, the quality of life of caregivers increased significantly ( $P = 0.024$ ). In caregivers with insufficient income, the quality of life was on average 10.5 units higher than caregivers with sufficient income ( $P = 0.038$ ).

In terms of employment status, the results showed that the quality of life was 6.54 units higher in self-employed

**Table 1** Frequency distribution of the Caregiver Quality of Life Index-Cancer (CQOLC) Scale in terms of demographic variables of caregivers

Variables	No (%)	Total score of CQOLC scale, mean $\pm$ SD	P-value
Age	< 40	216 (80.0)	<b>68.6</b> $\pm$ 15.6
	$\geq$ 40	54 (20.0)	74.1 $\pm$ 19.4
Gender	Male	81(30.0)	73.2 $\pm$ 17.1
	Female	189(70.0)	68.2 $\pm$ 16.1
Relationship with patients	Parent	246(91.2)	69.4 $\pm$ 16.5
	Sibling	12(4.4)	70.7 $\pm$ 20.3
	Other	12 (4.4)	75.4 $\pm$ 11.5
Marital status	Single	26(9.6)	73.9 $\pm$ 17.7
	Married	244(90.4)	69.3 $\pm$ 16.4
Education	Primary	77(28.5)	66.3 $\pm$ 16.3
	Secondary	53(19.6)	69.5 $\pm$ 14.2
	High school diploma	98(36.3)	71.2 $\pm$ 16.1
	Academic	42(15.6)	72.7 $\pm$ 19.8
Job	Unemployed	195 (72.2)	68.1 $\pm$ 16.2
	Employed	22 (8.2)	71.9 $\pm$ 17.4
	Self-employed	53 (19.6)	74.7 $\pm$ 16.5
Monthly income	Insufficient for expenses	257 (95.2)	69.3 $\pm$ 16.5
	Sufficient for expenses	13 (4.8)	79.8 $\pm$ 12.6
Average caring time, hours	1–6	30 (11.1)	74.1 $\pm$ 13.6
	7–12	64 (23.7)	73.8 $\pm$ 17.7
	13–18	43 (15.9)	70.5 $\pm$ 12.2
	19–24	133 (49.3)	66.4 $\pm$ 17.2

caregivers than unemployed caregivers ( $P=0.011$ ). With increasing care hours, the quality of life showed a significant decrease ( $p=0.021$ ). With an increase of one year in the patient's age, the quality of life increased by an average of 0.64 units ( $P=0.011$ ). With an increase of 1 year in the patient's age, the quality of life increased by an average of 0.64 units ( $P=0.011$ ). There was no statistically significant relationship between caregivers' quality of life and patient's gender, marital status, and caregiver's family relationship with the patient. There was no statistically significant relationship between caregivers' quality of life and their marital status, their family relationship with the patient, and patient's gender (Table 3).

## Discussion

The aim of this study was to determine the quality of life and its related factors in the caregivers of children with cancer in Iran. The results showed that the quality of life in caregivers was not satisfactory and was at a moderate level based on the score obtained from the CQOLC. Studies in Sri Lanka (2020), Singapore (2017), and Madison (2012) have reported poor quality of life for cancer caregivers

[7, 16, 17]. However, the results of two studies in Canada (2020) and Sri Lanka (2012) showed that the majority of caregivers of children with cancer had a good quality of life [18, 19]. Differences in results may be related to differences in sociodemographic characteristics of research samples as well as study instruments. Evidence suggests that the diagnosis of cancer in a child puts a lot of stress on the patients and their caregivers [20], which leads to a reduction in their quality of life. Decreased quality of life of caregivers can reduce the quality of care as well as the quality of life of patients [3]. Therefore, the quality of life of caregivers should be considered to improve the quality of care for children with cancer.

Examination of the dimensions of caregivers' quality of life showed that the lowest and highest scores for the "financial concerns" and "mental/emotional burden" dimensions, respectively. The study of Khanjari et al. (2013) in Iran on the quality of life of caregivers of children with leukemia showed a similar result [21]. This finding indicates more attention should be paid to the economic situation and the psychological well-being of caregivers. In this regard, referring the caregivers with financial burdens to support centers can reduce their economic burden. In addition, identifying the emotional needs

**Table 3** Factors associated with quality of life by liner regression model ( $N=270$ )

Variables	No (%)	<i>B</i>	<i>SE</i>	95% <i>CI</i>	<i>P</i> -value	
Age, year	< 40	216 (80)	Ref	-	-	-
	≥ 40	54 (20)	5.50	2.54	0.5, 10.5	.031
Gender	Male	81 (30)	Ref	-	-	-
	Female	189 (70)	-5.08	2.19	-9.39, -0.78	.021
Relationship with patients	Parent	246 (91.2)	Ref	-	-	-
	Sibling	12 (4.4)	1.35	4.90	-8.29, 10.99	.783
	Other	12 (4.4)	6.06	5.11	-4, 16.11	.237
Marital status	Married	244 (90.4)	Ref	-	-	-
	Single	26 (9.6)	4.60	3.47	-2.23, 11.44	.186
Education	Illiterate	77 (28.5)	Ref	-	-	-
	Primary	53 (19.6)	3.22	2.96	-2.62, 9.05	.279
	Secondary	98 (36.3)	4.83	2.52	-0.13, 9.79	.056
	Academic	42 (15.56)	6.38	3.22	0.05, 12.72	.048
Income	Insufficient for expenses	257 (95.2)	Ref	-	-	-
	Sufficient for expenses	13 (4.8)	10.54	5.06	0.57, 20.5	.038
Job	Unemployed	195 (72.2)	Ref	-	-	-
	Employed	22 (8.2)	3.78	3.85	-3.81, 11.36	.328
	Self-employed	53 (19.6)	6.54	2.54	1.53, 11.54	.011
Average care time (hours)	1–6	30 (11.1)	Ref	-	-	-
	7–12	64 (23.7)	-0.29	3.61	-7.4, 6.82	.936
	13–18	43 (15.9)	-3.57	3.87	-11.19, 4.06	.358
	19–24	133 (49.3)	-7.66	3.30	-14.16, -1.17	.021
Child's gender	Male	142 (52.6)	Ref	-	-	-
	Female	128 (47.4)	-2.25	2.03	-6.25, 1.75	.269
Child's age (year)	-	-	0.64	0.25	0.15, 1.14	.011

of caregivers and teaching the adaptive skills to them can also be effective in reducing their emotional burden [21, 22]. In this regard, the results of a study in Iran indicated the effectiveness of teaching coping skills in increasing the quality of life and its dimensions in the caregivers [23].

Contrary to previous studies [7, 24], in the current study, caregivers over the age of 40 years had a better quality of life than those under the age of 40 years. However, Khanjari et al. (2013) reported no statistically significant relationship between the age of caregivers and their quality of life [21]. Older caregivers are expected to have more experience to manage the challenges associated with child care and to use adaptive mechanisms more effectively to manage their care burden.

Consistent with previous studies [11, 22, 25], the quality of life of female caregivers was significantly lower than that of male caregivers. In a study by Nurhidayah et al. (2020) in Indonesia, male caregivers had a lower quality of life than female caregivers [7]. Due to the chronic nature of cancer, treatment of children with cancer is mostly done at home [3] and according to Iranian culture, mothers play the main role of caregiver for their family members because they believe that no one can take care of the patient as much as they do [26]. For this reason, and given the longer time Iranian mothers spend with a sick child, they are expected to experience more stress and therefore have a lower quality of life. The lower quality of life of female caregivers may also be due to the need for male caregivers to hide their weakness [22].

In line with the literature [8], with increasing education level, the quality of life of caregivers increased significantly. On the other hand, the results of a study in Indonesia (2020) showed that caregivers with low quality of life had primary education [7]. In another study on the caregivers of children with leukemia and brain tumors, a negative correlation was found between caregivers' level of education and their quality of life [8]. However, some studies have indicated no statistically significant relationship between caregivers' level of education and their quality of life [9, 21]. Differences in the results of studies can be due to the use of different tools as well as the sociodemographic characteristics of caregivers. However, highly educated caregivers are expected to have more problem-solving and decision-making skills, which will help them manage stress-related care and adapt to stress [27, 28]. Our findings indicate special attention should be paid to caregivers with low levels of education.

An unexpected finding was that caregivers with insufficient income had a better quality of life than those with adequate income. Caregivers seem to have adapted to their financial situation. In the study of Morhun et al. (2020) in Canada, no statistical relationship was found between the

income level and quality of life of caregivers [19]. In some studies, caregivers with low income had lower quality of life [7, 26]. However, the costs of leukemia care and treatment are high and put a lot of financial burden on the family [16], thereby reducing their quality of life [10]. In this regard, a study by Liu et al. (2021) in China showed that the costs of caring for a child with cancer were high, which affected their quality of life [29].

Consistent with the literature [21, 24], the results showed that the quality of life was significantly higher in self-employed caregivers than unemployed caregivers. Employed caregivers are usually in a better financial position [21], which naturally affects their quality of life.

The results showed that the quality of life of caregivers significantly decreased with an increase in the hours of patient care. Consistent with the present study, the results of Franchini et al. (2020) also showed that high hours of patient care are associated with worse quality of life [22]. Obviously, the longer the patient is cared for, the less time the caregivers will have to meet their personal needs.

In the present study, the quality of life of caregivers increased on average with an increase of 1 year in the patient's age. Evidence suggests that the patient's younger age is associated with greater care burden and therefore worse quality of life [30]. However, some studies have shown no relationship between the patient's age and the caregivers' quality of life [22].

The results showed no statistically significant relationship between child's gender and caregivers' quality of life. Contrary to current results, Franchini et al. (2020) showed the caregivers of male patients had worse quality of life [22]. According to Iranian culture, Iranians love their children of any gender and do not discriminate between them, and this is quite evident when their children become ill.

Inconsistent with the literature [24], our results showed that marital status did not have a statistically significant relationship with caregivers' quality of life. Care burden may affect the quality of life of the caregivers, whether single or married [8]. Differences in the results may be related to differences in the living conditions as well as sociodemographic characteristics of the caregivers. Our findings show the need for special and comprehensive attention to all caregivers, whether single or married.

In the present study, no statistically significant relationship was found between the caregivers' quality of life and their family relationship with the patient. Having a child with cancer seriously challenges the lives of all family members, including parents and siblings, and affects their quality of life [2, 8, 19, 21, 22]. This finding demonstrates the need for comprehensive economic, educational, and counseling support for the sick child's family members.

## Limitations

This study faced several limitations. Firstly, the data were collected by self-reporting method, which may have affected the accuracy of the results. Secondly, the study was conducted in a public hospital, which may, but not necessarily, affect the generalizability of the results. However, Mohammad Kermanshahi Hospital is the main center of pediatric cancer in western Iran and covers a diverse population. Thirdly, due to the nature of cross-sectional studies, it is not possible to determine the cause-and-effect relationships between the studied variables, and the current study is no exception to this rule.

## Conclusions

The mean age of patients was  $1.6 \pm 1.6$  years, and 53.0% were male. The mean age of caregivers was  $35.7 \pm 7.0$  years, and most of them were female, married, unemployed, parents of children, and had high school diploma. The mean care time was 18 h. The caregivers of children with cancer did not have a good quality of life. Variables related to quality of life included age, sex, education, occupation, economic status, length of care, and age of the child. Decreased caregivers' quality of life may affect the quality of care received by children with cancer. Therefore, a useful solution is to provide comprehensive educational, emotional, and economic support to the caregivers of these patients. Future studies are recommended to investigate the effect of interventional measures on the caregivers' quality of life.

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**Author contribution** MC, SR, MJ, and AK contributed to the design of the study. MC collected the data. SR analyzed the data. MC, SR, MJ, and AK wrote the final draft. All the authors read and approved the version for submission.

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**Data availability** The identified datasets analyzed during the current study are available from the corresponding author on a reasonable request.

## Declarations

**Ethics approval** The ethics committee of Kermanshah University of Medical Sciences approved the study with the code IR.KUMS.REC.1397.1016.

**Consent to participate** Written informed consent was obtained from the participants.

**Consent for publication** Not applicable.

**Competing interests** The authors declare no competing interests.

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