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The Predictive Role of Perceived Social Support and Family-Centered Care in the Quality of Life of Parents of Children with Cancer

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ABSTRACT

Aim: This study aimed to determine the predictive role of perceived social support and family-centered care in the quality of life of parents who had children with cancer.

Material and Methods: This study used a descriptive, methodological, and cross-sectional design. The study data were collected using a Parent Information Form, the Multidimensional Scale of Perceived Social Support, the Family-Centered Care Assessment Scale, and the Caregiver Quality of Life Index-Cancer. Mean scores, percentage calculations, t-test, ANOVA test, and linear regression analysis were used to analyze the study data.

Results: A statistically highly significant difference was found between the age, sex, education level, employment status, income status of the parents of the child with cancer, and the age and the duration of hospitalization of the child and the mean perceived social support, family-centered care assessment, and quality of life scale scores. In model 1, perceived social support of parents explained 54.9% of the level of their quality of life. In Model 2, family-centered care assessments of parents explained 54.9% of the level of their quality of life.

Conclusion: This study is valuable in that it demonstrating the effect of perceived social support and family-centered care assessments on the quality of life. Nurses should keep in mind that parents who have little perceived social support and cannot access family-centered care may have a low quality of life. Therefore, nursing care plans should also address these variables.

Keywords: Perceived social support; family-centered care; quality of life; cancer; parent.

Sosyal Destek Algısı ve Aile Merkezli Bakımın Kanserli Çocukların Ailelerinin Yaşam Kalitesine Etkisi

ÖZ

Amaç: Bu çalışmanın amacı, algılanan sosyal destek ve aile merkezli bakımın kanserli çocuğu olan ebeveynlerin yaşam kalitesi üzerindeki yordayıcı rolünü belirlemektir.

Gereç ve Yöntemler: Bu çalışmada tanımlayıcı, metodolojik ve kesitsel bir tasarım kullanılmıştır. Araştırmanın verileri Ebeveyn Bilgi Formu, Çok Boyutlu Algılanan Sosyal Destek Ölçeği, Aile Merkezli Bakım Değerlendirme Ölçeği ve Bakım Veren Yaşam Kalitesi İndeksi-Kanser kullanılarak toplanmıştır. Araştırma verilerinin analizinde ortalama puanlar, yüzde hesaplamaları, t-testi, ANOVA testi ve doğrusal regresyon analizi kullanılmıştır.

Bulgular: Kanserli çocuğun yaşı, cinsiyeti, eğitim düzeyi, çalışma durumu, anne-babanın gelir durumu ile çocuğun yaşı ve hastanede kalış süresi ile algılanan sosyal destek, aile merkezli bakım değerlendirmesi ve yaşam kalitesi ölçeği puan ortalamaları arasında istatistiksel olarak ileri düzeyde anlamlı farklılık bulunmuştur. Model 1'de ebeveynlerin algılanan sosyal desteği yaşam kalitelerinin %54,9'unu açıklamaktadır. Model 2'de ebeveynlerin aile merkezli bakım değerlendirmeleri onların yaşam kalitesi düzeyinin %54,9'unu açıklamaktadır.

Sonuç: Bu çalışma algılanan sosyal destek ve aile merkezli bakım değerlendirmelerinin yaşam kalitesi üzerindeki etkisini ortaya koyması açısından değerlidir. Hemşireler, algılanan sosyal desteği az olan ve aile merkezli bakıma erişemeyen ebeveynlerin yaşam kalitesinin düşük olabileceğini akılda tutmalıdır. Bu nedenle hemşirelik bakım planlarının bu değişkenleri de ele alması gerekir.

Anahtar Kelimeler: Algılanan sosyal destek; aile merkezli bakım; yaşam kalitesi; kanser; ebeveyn.

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INTRODUCTION

Childhood cancers cause children to experience many symptoms depending on both the nature of the disease and the side effects of treatment. All these symptoms restrict physical activity and social life, increase dependence on caregivers, cause psychosocial problems, and affect the quality of life (1). During this process, parents who give care to the child have to cope with many physiological and psychosocial problems (2). Parents both try to cope with the situation they are in and take the responsibility of supporting and giving care of the sick child. During this period, parents need to share their experiences and require perceived social support (2). The family-centered care implemented by pediatric nurses is a significant place in providing the necessary social support. The goals of the family-centered care that the nurse will administer include providing services that parents need and keeping parents connected to social support networks (3).

Perceived social support refers to a person's belief about how well their needs related to social support, such as information, are being met (4). Sharing situations such as childcare, housework, taking care of other children with a person a source of support in chronic diseases such as cancer and evaluating the reactions of individuals about the subject will support family members to develop a perspective. The availability of perceived social support resources is of great importance in cases, such as planning the process of the disease, decision-making about treatment, financial needs, and moral and emotional breakdowns, and it enhances the capacity of family members to cope with the situation (5). In the study conducted by Pietnoczko and Steuden (6) with the parents of 89 children with cancer, a connection was determined between the social support perceived by parents and health problems. Today, it is seen that the standard social examination reports in Turkey include issues related to perceived social support. However, it is said that a model is needed to obtain more systematic information (7).

Family-centered care, which is adopted as one of the basic philosophies of pediatric nursing, sees the family as a constant element of the child's life. The family is at the core of the child's existence and should also be at the center of the hospital care process (8). Family-centered care allows parents to participate in the care of the child and recover the sense of control they have lost by developing a sense of mutual trust through effective communication between parents and healthcare professionals. Also, parents of children with cancer who receive family-centered care state that they perceive this care as social support and that they feel better (9,10). Although family-centered care philosophy is included in health education in Turkey, the number of centers that include family-centered care in institutional policies is unfortunately limited. In addition, the number of centers where family-centered care is applied cannot be reached.

For parents to maintain the chronic disease process in the best way, it is necessary to arrange their relationship with the child and their parent-parent relationship effectively. The support received by parents is important for family members to express themselves (6). Integrating a family-centered approach to care can improve social support perceptions (6). Besides, the provision of family-centered care by nurses in cancer and other chronic diseases is extremely important for increasing the quality of life (6). Through this support, parents create a structure that will help them easily manage the disease. The family-centered work model ensures that parents adapt to everyday life and disease conditions more easily and that their quality of life increases (6).

Quality of life is a multi-factor concept that covers many areas. But according to the generally accepted opinion, quality of life is a concept that should include functional competence, complaints associated with illness and treatment, competence in psychological and social functions (11,12). The quality of life of the parents of children with cancer is highly affected by various factors such as difficulties experienced in the treatment process of the child, frequent hospitalization, worsening of the prognosis, financial difficulties, and lack of social support (13). Perceived social support and family-centered care variables support people to provide this qualification and significantly affect their quality of life. It is noted that perceived social support acts as a buffer in protecting the individual from the harmful effects of stressful life events (14). A cancer diagnosis, especially of a child in a family of people, both increases the need for social support and can reduce access to social support, leading to social stigma. A decrease in perceived social support for parents of children with cancer leads to a reduction in quality of life (14). The benefits of family-centered care, one of the other important variables affecting quality of life, include increased parent self-sufficiency, improved information flow, improved interaction between the family and the professional team, and, as a result, improved parent's quality of life (3,12). Although psychosocial concepts such as social support and quality of life in children with cancer are not the main factors in the positive course of prognosis, they have important effects on the recovery of the child (3). Family-centered care, on the other hand, is an indispensable aspect of pediatric nursing, which includes these two concepts and has positive effects for both the child and the family. In this context, it is very important to study these three concepts together, which are related separately. Identifying the relationship between the three variables will contribute to planning initiatives that will improve the quality of life of parents (12).

The perceived social support, family centered care and quality of life of parents who have children with cancer is a current and important issue in professional nursing (9). In the literature, while there are studies that examine these three important variables separately (13–19), no studies showing the relationship between them have been found. For this reason, there is a need for studies examining the effect of perceived social support and family-centered care on the quality of life of parents of children with cancer.

Aim

This study was designed to ascertain the predictive contributions of perceived social support and family-centered care to the quality of life among parents of children diagnosed with cancer.

Research Questions

1. What are the mean scores of parents of children with cancer for perceived social support, family-centered care, and quality of life?

2. Do perceived social support, family-centered care, and quality of life show a difference according to sociodemographic and disease-related characteristics?
3. What is the predictive role of perceived social support and family-centered care in the quality of life of parents of children with cancer?

MATERIAL AND METHODS

Aim and Study Design

This study, which used a descriptive and cross-sectional research approach, was conducted at the pediatric oncology-hematology clinic of a prominent university hospital in Turkey between September 22 and November 30, 2020.

Participants

The study group included individuals who (a) were aged over 18, (b) had a child diagnosed with cancer, (c) had no psychiatric diagnosis and communication problems, and (d) volunteered to participate in the study. The determination of the minimum requisite sample size for the study was conducted through the utilization of GPOWER 3.0 statistical analysis software. The calculated sample size, determined to be 135 subjects, is deemed adequate for conducting linear regression analysis. This calculation was based on consideration of 14 variables, with a significance level set at 0.05, a statistical power of 80%, and a medium effect size of 0.15 (20).

A total of 246 people were evaluated for eligibility. On the other hand, individuals with communication problems (n = 1) and refusing to participate (n = 5) were not included in the study. Therefore, parents of 240 children with cancer were included in the study (Figure 1).

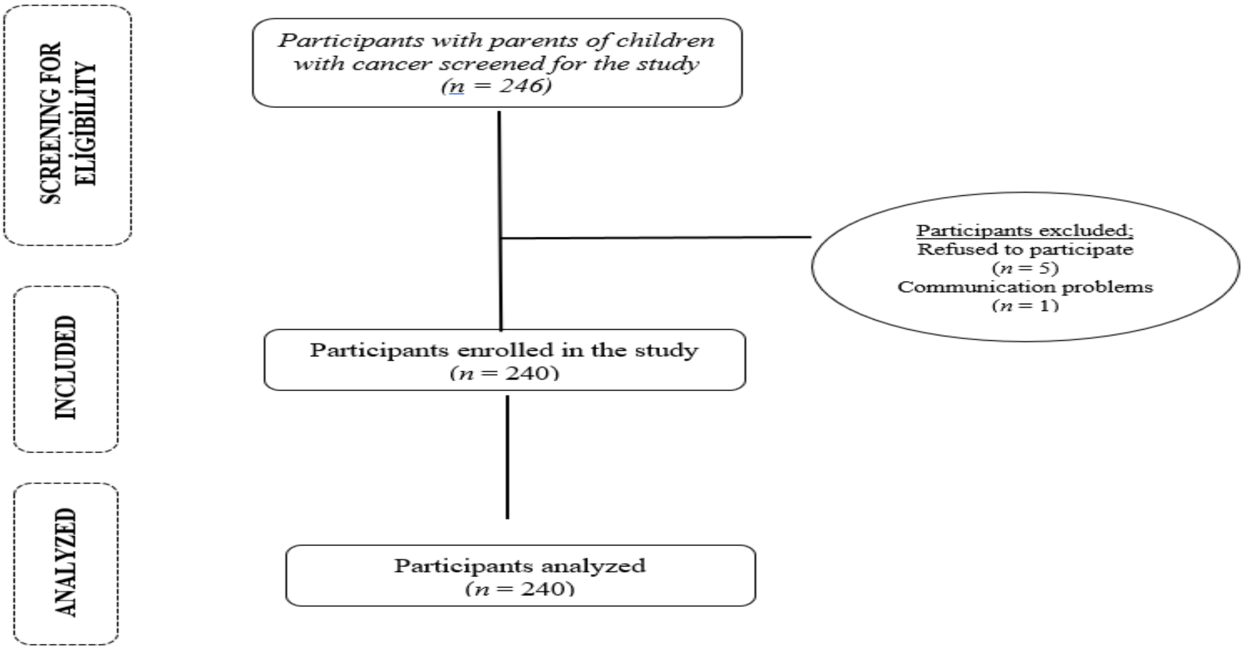

Figure I. Participant flow diagram.

Data Collection Tools

In this study, data were collected using The Parent Information Form, The Multidimensional Scale of Perceived Social Support, The Family-Centered Care Assessment Scale and The Caregiver Quality of Life Index-Cancer.

The Parent Information Form, devised by the researchers and informed by pertinent literature, comprises 12 items. Its objective is to gather data on variables that may influence parents' perceived social support and quality of life. These variables encompass the parent's age, gender, educational and employment status, and income, along with details regarding the child's age, gender, diagnosis, and duration since diagnosis. Additionally, the form captures information on family type, the presence of support-providing individuals, and the frequency of interactions among family members (3,10).

The Multidimensional Scale of Perceived Social Support (MSPSS), developed by Zimet et al. (4), underwent a Turkish validity and reliability study conducted by Eker and Akar (21), with subsequent revisions in 2001 by the same authors. Comprising 12 items, the scale encompasses three subscales, each consisting of 4 items that inquire about the source of support, namely family, friends, and a special person. Responses are recorded on a 7-point Likert-type scale, where higher scores signify elevated perceived social support. The overall internal consistency coefficient of the scale is reported as 0.89 (4,21). In this study, the Cronbach alpha value of the scale was found to be 0.88.

The Family-Centered Care Assessment Scale (FCCAS), developed by Arslan et al. (22), underwent validation and reliability testing in the Turkish context. This five-point Likert-type scale comprises 21 items, rated on a scale of 1 (never) to 5 (always), distributed across three subscales: support, cooperation, and respect. The Cronbach's alpha coefficient for the overall scale is reported as 0.72, and factor loading values range from 0.46 to 0.75. The scale's scoring ranges from 21 to 105, with higher scores indicating an increased parental perception of family-centered care (22). In this study, the Cronbach alpha value of the scale was found to be 0.78.

The Caregiver Quality of Life Index-Cancer (CQOLC), developed by Weitzner et al. in 1999 (23), underwent Turkish validity and reliability assessment by Bektas and Özer (24). This scale is designed to assess the impact of caregiving on the quality of life and comprises 25 items distributed across four subscales: physical functions, emotional functions, family functions, and social functions. Responses to scale items are recorded on a Likert-type scale ranging from 0 (not at all) to 4 (very much). The overall CQOLC score is derived by summing the scores of the 25 items, with reverse scoring applied to items with negative expressions. The total scale score ranges from 0 to 100, where higher scores indicate better quality of life. The overall internal consistency coefficient for the scale is reported as 0.88, and specific coefficients for the burden, discomfort, positive adaptation, and financial problems subscales are 0.83, 0.79, 0.73, and 0.77, respectively (23,24). In this study, the Cronbach alpha value of the scale was found to be 0.90, and the Cronbach alpha value for the burden, discomfort, positive adaptation, and financial problems subscales are 0.85, 0.80, 0.75, and 0.79, respectively.

Data Collection Procedure

Initially, all participants were duly apprised of the study's objectives and were requested to provide informed consent by signing a consent form. Subsequently, the principal researcher acpuired data through in-person interviews employing the parent information form, MSPSS, FCCAS, and CQOLC instruments. The data collection process for each participant consumed approximately 15-20 minutes.

Ethical Considerations

Initially, permissions from the owners of the employed measurement scales were obtained through electronic correspondence. Furthermore, institutional approval was secured, as the study garnered endorsement from the Dokuz Eylül University Non-Interventional Clinical Research Ethics Committee (Issue: 5666-GOA, 2020 / 22-01). The principal investigator expounded upon the study's objectives and procured verbal and written informed consent from each participant. Participants were explicitly afforded the option to withdraw from the study at any juncture without the necessity to furnish a justification.

Statistical Analysis

The data were analyzed using IBM SPSS Statistics version 23.0 (IBM Corp). Tests of normality, namely the Shapiro-Wilk test, histogram, and normal Q-Q plot, were employed for assessing normal distribution. Categorical variables were presented as frequency and percentage values, while normally distributed characteristics were summarized using mean and standard deviation values. To examine the influence of sociodemographic and disease-related characteristics on MSPSS, FCCAS, and CQOLC scores, T-test and ANOVA tests were conducted. The Bonferroni-corrected Mann-Whitney U test was employed to identify differences in age, educational status, and the age of the child. The predictive capacity of perceived social support and family-centered care assessment on caregivers' quality of life was assessed through linear regression analysis. To examine multicollinearity among perceived social support, family-centered care assessment, and caregivers' quality of life, VIF and tolerance analyses were performed, with inclusion criteria set at VIF < 10, tolerance < 0.2, and condition index < 15 for independent variables (25). Results were interpreted with a 95% confidence interval, and statistical significance was set at p < 0.05.

RESULTS

According to the study findings, a significant proportion of participating parents (55.8%) fell within the 20-29 age group, with a predominant female representation (77.5%). Furthermore, 32.1% of parents reported a high school education, 53.8% were unemployed, 79.2% belonged to nuclear families, and 60% experienced financial strain with income falling short of expenses. Regarding the children involved, 75% were in the 0-5 age bracket, 31.3% were diagnosed with Acute Lymphoblastic Leukemia (ALL) and Acute Myeloid Leukemia (AML), 53.2% received a cancer diagnosis within the last 0-2 months, and 64.2% had hospitalizations lasting more than 7 days. Additionally, 60% of parents received support from their spouses, while 51.2% could only engage with their families once a week during their hospital stay. Statistical analyses showed that parents were homogeneously distributed regarding sociodemographic and disease-related variables (p>0.05).

The mean scores obtained by the parents in the study from MSPSS, FCCAS, and CQOLC scales are given in Table 1. A statistically significant difference was observed in the mean scores derived from MSPSS, FCCAS, and CQOLC scales based on various demographic variables, including the age, sex, education level, employment status, income status of parents of children with cancer, the age of the child, and the duration of hospitalization (p<0.05). However, no statistically significant difference was found in the mean scores based on the diagnosis and time of diagnosis (p>0.05, Table 2). Additionally, a statistically significant difference was noted between family type and the individual providing support in relation to MSPSS and FCCAS mean scores (p<0.05). However, no statistically significant difference was observed between these two variables and CQOLC mean scores (p>0.05, Table 2).

Table 1. Parents' mean scores from MSPSS, FCCAS, and CQOLC (n = 240)

	Minimum	**Maximum**	**Mean**	**SD**
MSPSS	15.00	78.00	41.72	29.13
MSPSS Family Sub-scale	5.00	26.00	13.94	9.68
MSPSS Friends Sub-scale	5.00	27.00	14.26	10.16
MSPSS Significant Other Sub-scale	5.00	25.00	13.51	9.28
FCCAS	30.00	105.00	56.03	34.24
FCCAS Support Sub-scale	14.00	50.00	26.04	16.70
FCCAS Cooperation Sub-scale	10.00	40.00	21.47	12.96
FCCAS Respect Sub-scale	5.00	15.00	8.51	4.61
CQOLC	14.00	75.00	44.85	25.94

MSPSS: Multidimensional Scale of Perceived Social Support; FCCAS: Family-Centered Care Assessment Scale; CQOLC: Caregiver Quality of Life Index-Cancer; SD: Standart Deviation

Table 2. The effects of parents' sociodemographic and disease-related features on mean MSPSS, FCCAS, and CQOLC scores

		MSPSS	**FCCAS**	**CQOLC**
		Mean ± SD	**Mean ± SD**	**Mean ± SD**
Age (years)	20-29 years	20.99 ± 14.66	33.73 ± 14.08	32.18 ± 22.22
	30-39 years	64.58 ± 23.07	81.18 ± 33.16	60.63 ± 21.67
	40-49 years	75.00 ± 10.36	90.67 ± 26.32	61.38 ± 19.89
	Test value ^{a}p	*F: 225.072* ***p: 0.000***	*F: 142.324* ***p: 0.000***	*F: 51.487* ***p: 0.000***
Gender	Female	37.32 ± 27.96	51.37 ± 32.35	42.29 ± 25.74
	Male	56.85 ± 28.22	72.11 ± 35.99	53.70 ± 24.86
	Test value ^{b}p	*t: -4.508* ***p: 0.000***	*t: -3.811* ***p: 0.000***	*t: -2.945* ***p:0.004***
Educational Level	Primary School	16.15 ± 4.16	15.68 ± 9.89	24.57 ± 14.57
	Middle School	19.01 ± 10.05	18.12 ± 10.79	33.43 ± 23.06
	High School	50.24 ± 28.77	65.00 ± 36.04	50.70 ± 25.88
	Graduate	73.33 ± 12.81	90.49 ± 27.13	62.24 ± 19.65
	Postgraduate	-	-	-
	Test value ^{a}p	*F: 119.423* ***p: 0.000***	*F: 78.842* ***p: 0.000***	*F: 26.895* ***p: 0.000***
Working Status	Yes	*58.48 ± 27.55*	*74.09 ± 35.20*	*53.54 ± 24.50*
	No	*27.29 ± 21.87*	*40.50 ± 24.46*	*37.37 ± 24.87*
	Test value ^{b}p	*t: 9.603* ***p: 0.000***	*t: 8.447* ***p: 0.000***	*t: 5.061* ***p: 0.000***
Income Status	Less than income	*25.82 ± 20.92*	*38.79 ± 22.00*	*35.45 ± 23.95*
	Income is equal to expenses	*65.95 ± 22.76*	*81.89 ± 33.09*	*58.95 ± 22.24*
	More than income	-	-	-
	Test value ^{a}p	*F: 193.492* ***p: 0.000***	*F: 146.930* ***p: 0.000***	*F: 58.653* ***p: 0.000***
Child's age (years)	0-5 years	*32.57 ± 25.95*	*46.20 ± 29.58*	*39.44 ± 25.28*
	6-10 years	*63.72 ± 23.63*	*80.81 ± 32.80*	*60.48 ± 21.84*
	11-18 years	*75.77 ± 8.67*	*91.33 ± 26.19*	*61.85 ± 19.66*
	Test value ^{a}p	*F: 52.594* ***p: 0.000***	*F: 40.446* ***p: 0.000***	*F: 17.917* ***p: 0.000***
Diagnosis of the Child	Acute Lymphoblastic Leukemia - Acute Myeloid Leukemia	*45.44 ± 30.17*	*58.05 + 34.69*	*45.66 + 26.17*
	Central Nervous System Tumor	*36.72 ± 27.68*	*52.30 ± 33.19*	*43.35 ± 26.08*
	Solid Tumors	*42.25 ± 28.03*	*57.62 ± 35.35*	*48.20 ± 26.67*
	Other Tumors	*42.42 ± 30.07*	*56.71 ± 34.65*	*43.24 ± 25.37*
	Test value ^{a}p	*F: 1.092* ***p: 0.353***	*F: 0.389* ***p: 0.761***	*F: 0.392* ***p: 0.759***
Length of Stay in the Hospital	Less than 7 days	*63.33 ± 25.07*	*79.17 ± 34.01*	*57.11 ± 23.53*
	7 days and over	*29.64 ± 23.81*	*43.11 ± 26.83*	*38.01 ± 24.74*
	Test value ^{b}p	*t: 10.160* ***p: 0.000***	*t: 8.468* ***p: 0.000***	*t: 5.919* ***p: 0.000***
Child's Diagnosis Time	0-2 months	*40.91 ± 29.57*	*56.07 ± 34.48*	*43.36 ± 25.69*
	3-5 months	*40.47 ± 28.15*	*54.25 ± 33.60*	*45.96 ± 26.38*
	6 months and above	*60.75 ± 28.05*	*70.50 ± 36.41*	*51.58 ± 25.51*
	Test value ^{a}p	*F: 2.741* ***p: 0.067***	*F: 1.209* ***p: 0.300***	*F: .703* ***p: 0.496***
Family Type	Nuclear family	*45.71 ± 29.63*	*60.13 ± 35.34*	*45.65 ± 25.83*
	Large family	*26.54 ± 21.32*	*40.46 ± 24.25*	*41.84 ± 26.39*
	Test value ^{b}p	*t: 5.177* ***p: 0.000***	*t: 4.594* ***p: 0.000***	*t: .913* ***p: 0.364***
Get Support Person	Wife/husband	*35.75 ± 27.33*	*48.38 ± 30.58*	*42.39 ± 25.86*
	Family	*50.67 ± 29.58*	*67.52 ± 36.33*	*48.55 ± 25.75*
	Friend	-	-	-
	Other persons	-	-	-
	Test value ^{a}p	*F: 16.078* ***p: 0.000***	*F: 19.374* ***p: 0.000***	*F: 3.274* ***p: 0.072***

*^{a}ANOVA Test; ^{b} t Test;*p<0.05; SD: Standard Deviation*

Post hoc analysis using the Bonferroni-corrected Mann-Whitney U test revealed that the observed differences stemmed from the parent's age variable, particularly within the 20-29 age group, the level of education variable, specifically among parents with elementary and middle school education, and the age of the child variable, particularly within the 0-5 age group.

In the multiple regression analysis, a model was established to delineate the impact of perceived social support received by parents of children with cancer on their quality of life. According to Model 1, an increase in perceived social support corresponded to an elevation in the quality of life among parents. The model indicated that parents' perceived social support accounted for 54.7% of their quality of life varience. Notably, the family (β = 0.078), friends (β = 0.293), and other special persons (β = 0.079) subscales of the Multidimensional Scale of Perceived Social Support were identified as significant contributors to parents' quality of life (p > 0.05, Table 3).

Table 3. The level by which perceived social support of parents predicted their quality of life (n=240)

	Caregiver Quality of Life Index-Cancer						
	Model 1						
	Unstandardized Beta	Standard Error	Standardized Beta β	t	p	95 % Confidence Interval	
						Lower	Upper
Multidimensional Scale of Perceived Social Support (MSPSS)							
MSPSS Family Sub-scale	0.135	0.062	0.078	2.182	0.029	0.102	0.205
MSPSS Friends Sub-scale	0.362	0.047	0.293	7.653	0.000	0.286	0.398
MSPSS Significant Other Sub-scale	0.187	0.080	0.079	2.330	0.020	0.176	0.209
R	0.739						
R^2	0.547						
F	94.931						
p	0.000						
Durbin Watson (1.5–2.5)	1.853						

R: correlation; R2: correlation coefficient (explained variance ratio); F: model statistics; p: level of significance

According to the relationship between variables in multiple regression analysis, the effect of family-centered care assessments of parents of children with cancer on their quality-of-life levels was specified as a model. According to Model 2, increased mean scores of the parents from the family-centered care assessment scale increased the levels of quality of life. In the model, parents' family-centered care assessments explained 54.9% of the levels of quality of life. It was found that the quality-of-life level of the parents was significantly affected by the support (β = 0.261) and cooperation subscales (β = 0.078) of the family-centered care assessment scale. It was found that the quality-of-life level of the parents was not statistically significantly affected by the respect subscale of the family-centered care assessment scale (p>0.05, Table 4).

Table 4. The level by which family-centered care assessment of the parents predicted their quality of life (n=240)

	Caregiver Quality of Life Index-Cancer						
	Model 2						
	Unstandardized Beta	Standart Error	Standardized Beta β	t	p	95 % Confidence Interval	
						Lower	Upper
Family-Centered Care Assessment Scale (FCCAS)							
FCCAS Support Sub-scale	0.404	0.049	0.261	8.289	0.000	0.398	0.463
FCCAS Cooperation Sub-scale	0.135	0.062	0.078	2.182	0.028	0.128	0.158
FCCAS Respect Sub-scale	-0.004	0.45	-0.002	-0.079	0.937	-0.016	-0.002
R	0.741						
R^2	0.549						
F	95.948						
p	0.000						
Durbin Watson (1.5–2.5)	2.383						

R: correlation; R^2: correlation coefficient (explained variance ratio); F: model statistics; p: level of significance

DISCUSSION

Childhood cancers are a health problem that causes disturbing symptom burden, decreases the quality of life, restricts both children and their parents throughout the entire illness, where family-centered care and perceived social support are important. Parents of children with cancer face many major challenges during this process (26). Considering the current literature, although the quality of life, perceived social support, and family-centered care in parents of children with cancer have been investigated as separate variables (13,15,16), as far as we know, this is the first study to examine the three variables together. This study unveiled statistically significant disparities in the mean scores of perceived social supports, family-centered care assessment, and quality of life scale across diverse demographic variables. These factors encompassed the age, gender, educational attainment, employment status, and income level of parents with children diagnosed with cancer, as well as the age and duration of hospitalization of the affected child.

Turkish society has a family union that includes several generations living together, and extended parents are quite common. Therefore, parents' social support systems are well developed in Turkey (27). However, the mean perceived social support scale scores were found to be low, and this was thought to have stemmed from the fact that 79.2% of the participants had a nuclear family and that the social support decreased due to the long duration of chronic diseases such as cancer (41.72 + 29.13) (28,29). The chronic disease has a course that requires a long treatment and care process and causes an increased need for social support and decreased quality of life (28). Although the social support systems of individuals are strong in this period, this support may decrease over time due to the long process (28). Moreover, data for this study were gathered amid the backdrop of the COVID-19 pandemic, a contextual factor that may have exerted an influence on the observed outcomes. The COVID-19 pandemic has evolved into a multifaceted phenomenon, detrimentally impacting children grappling with chronic conditions such as cancer, along with their parents, both in terms of physical well-being and psychosocial dimensions (30,31). Due to the COVID-19 pandemic, parents had to restrict their social gatherings to protect against infection, face-to-face social relations had to be canceled, and parents were unable to request support from relatives when they needed help, all of which may have caused the perceived social support scale scores to be low. Considering the study results in the literature, the reasons for the low social support scores of the parents of children with cancer may be due to such differences (31). During the Covid-19 pandemic period in Turkey, some hospitals were completely dedicated to hematology-oncology patients, but the limited number of these hospitals may have reduced the perceived level of social support by limiting children and families from receiving family-centered care.

Family-centered care, which is one of the basic building blocks of pediatric nursing, also has an important place in the care of children with cancer and their parents (22). However, it is thought that the reasons for the low mean scores of the family-centered care assessment scale (56.03 + 34.24) of the participants may have been influenced by many factors. Among them, health professionals' busy working hours and the provision of care to a large number of patients may have come to the fore. In the literature, in the study of Boztepe and Kerimoğlu Yıldız (32), the most common obstacles faced by nurses when providing family-centered care were the intensive work pace and time management problems. Besides, the COVID-19 pandemic process may have increased the workload of healthcare professionals. Apart from this, it is thought that during the COVID-19 pandemic process, there may be problems in maintaining family-centered care due to reasons, such as the decrease in interpersonal interaction and the limitation of the time spent in patient rooms (33). According to the literature, parents attach importance to the time spent with nurses and the communication techniques employed when evaluating family-centered care (33). It is thought that reducing the time spent with patients and their families in order to reduce the risk of transmission during the Covid-19 period may have affected this situation. The low family-centered care assessment scale scores of the parents participating in the study may have been due to such differences.

The quality of life of caregivers of individuals diagnosed with cancer can be affected by many factors such as prognosis, survival rate, side effects of treatment, level of social support, quality of care, communication, family-centered care, stage of the disease, and type of treatment. Studies focus on the quality of life of parents as much as children with cancer (34,35). Nevertheless, it is thought that the mean scores of the participants from the quality of life scale may be low (44.85 + 25.94) due to reasons, such as the long duration of cancer treatment, the importance that people attach to their children, little social support, and dealing with many physical and psychosocial problems. Studies in the literature emphasize that many variables, including increased symptom burden of children, low perceived social support, and restricted social lives of parents, are effective in reducing the quality of life (11,29). The low quality of life scale scores of the parents participating in the study may have also been impacted by these differences.

Similar to previous study, it was determined in our study that factors, including the parents' age, gender, education level, employment and income status, age of the child, and the length of hospitalization, affected parents perceived social support, family-centered care assessment, and quality of life (34). The increased mean age of the parents, male gender, high education level, high income level, having a job, the increased mean age of the child, and shorter hospitalization period caused parents to get high scores from the perceived social support, family-centered care, and quality of life scales. The review of the literature indicated that the effect of the sociodemographic characteristics of the parents on the three main variables of the study was examined separately by several studies. Sociodemographic characteristics of parents such as age, number of children, gender, employment and educational status affect the meaning they give to social support and their coping mechanisms (5,9,36,37). Previous studies were also found to document these findings.

Upon scrutinizing the findings through the lens of the models devised in our study, Model 1 demonstrated a positive correlation, revealing that an elevation in the perceived social support among parents of children with cancer was associated with an improvement in their quality of life. One study corroborates the beneficial impact of social support on parents, underscoring a positive association with the child's level of adaptation to the disease process (6). Coping skills, social support, and symptoms and functionality of the child affect the parent’s quality of life (11,29). While the cancer diagnosis and treatment of the child increases the parents' need for social support, having a child with cancer can lead to social stigma and reduce access to social support especially when it is needed most (5). It has been stated in the literature that perceived support from family, friends or a special person has a positive relationship with the quality of life of people (11). The literature supports the finding in model 1. In this study, it was determined that the mean subscale scores of the perceived social support scale were significantly effective in predicting the effect on the quality of life ($p < 0.05$).

According to the findings in terms of the models we created in our study, Model 2 showed that increased mean scores of parents from the family-centered care assessment scale increased their level of quality of life. The purpose of family-centered care includes healthcare professionals' provision of support to the child and the parents, collaboration with the child and the parents and informing them and increasing the quality of life of the child and parents by reducing the problems related to the disease and treatment (10). Family-centered care includes basic elements, such as respect, sharing information, family involvement in care, and cooperation with the family (3). Studies conducted to evaluate the contribution of family-centered care to parents have shown that family-centered care increases collaboration and communication between parents and nurses, reduces parental anxiety and depression levels, shortens the hospitalization period, and improves the parents' quality of life (38–40).Therefore, in various studies, it has been determined that parents are aware of the benefits of family-centered care and want to be involved in the care process of the child in the hospital (40). In a study conducted with the parents of children with cancer investigating the effect of family-centered care on the care burden and quality of life of the parents, it was found that family-centered care reduced the care burden of parents and increased their quality of life (10). The findings in the literature were found to align with and support the outcomes observed in Model 2. Specifically, our study revealed that the mean scores of the support and cooperation subscale within the family-centered care assessment scale significantly influenced the prediction of their impact on the quality of life ($p < 0.05$). Conversely, the respect subscale exhibited no significant effect ($p > 0.05$). This discrepancy is conjectured to stem from the gravity of the cancer diagnosis, whereby parents, engrossed in prolonging their child's life, may prioritize support and cooperation over considerations of respect in their interactions with healthcare professionals.

Limitations

Notwithstanding several commendable aspects of this study, certain limitations warrant consideration. Firstly, the utilization of a convenience sample introduces a potential constraint, impacting the generalizability of the study findings. Secondly, the data collection occurred amid the backdrop of the COVID-19 pandemic, constituting a contextual factor that may have influenced the results. Thirdly, the inclusion of parents of children diagnosed with hematologic and oncologic cancer presents a limitation, as the specific diagnosis of the child represents a notable variable that can influence the family's quality of life. Future studies are encouraged to address this limitation by strategic planning and consideration of the diverse impact of different diagnoses on family outcomes. The final limitation is that the time the child is diagnosed with cancer, a factor that affects the parent's quality of life and perception of social support, has been overlooked. Future studies may be recommended to plan studies that include parents of children diagnosed with cancer at different stages.

CONCLUSION

This study is valuable in that it demonstrates the effect of perceived social support and family-centered care assessments on the quality of life. In this study, it was determined that various demographic variables such as age, gender, education level, employment status, income status of parents of children with cancer, age of the child and length of hospital stay affected the mean scores obtained from MSPSS, FCCAS and CQOLC scales. The trajectory of childhood cancer significantly impacts the quality of life for parents. This study is pivotal in elucidating the impact of perceived social support and family-centered care assessment on the quality of life among parents with children afflicted by cancer. Even in instances where cancer treatment attains success, the restoration of an everday life can entail a protracted and arduous process. Empowering parents to navigate this post-treatment phase with positive outcomes is imperative. Enhanced parental empowerment, crucial for an improved quality of life, can be achieved through augmenting perceived social support and implementing family-centered care initiatives. It is incumbent upon nurses to proactively engage in interventions that underscore their expanded roles. These interventions encompass the promotion of family-centered care practices, provision of social support, cultivation of coping skills, and sustained involvement with parents throughout the entirety of the cancer care continuum.

In light of the findings from this study, it is imperative for nurses to be cognizant of the potential impacts of perceived social support and family-centered care on the quality of life. When assessing the quality of life in clinical practice, nurses should systematically consider both perceived social support and family-centered care. Notably, nurses should be attentive to the fact that parents experiencing limited social support and facing challenges in accessing family-centered care may exhibit a diminished quality of life. Consequently, nursing care plans should incorporate considerations for these variables. Regular training programs focusing on the family-centered care approach in pediatric oncology clinics are essential. Furthermore, the routine implementation of family-centered care in clinics, along with its institutional adoption as a policy, is recommended. Consideration should be given to organizing hospital facilities to cater to the specific needs of parents and children, including designated spaces such as training rooms and interview rooms. Future research endeavors should explore the relationship between perceived social support, family-centered care, and quality of life in diverse populations to garner a more comprehensive understanding of these dynamics.

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