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The Role of Social Support and Caregiver Burdens among Parents of Children with Cancer

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ABSTRACT

Background: Cancer is the most common disease in the present century and the number of affected children is increasing. It can cause many problems for family caregivers**.** This study assessed the correlation between social support and care-giving burden among parents of children with cancer.

Methods: This cross-sectional descriptive study was conducted by convenience sampling method on 230 parents (115 mothers and 115 fathers) referring to Oncology Clinic and Oncology Ward in Yazd Shahid Sadoughi Hospital (Iran) from March to August 2020 (Covid-19 Pandemics). Researchers asked the patients' parents to answer the questionnaires. The data were gathered by the demographic questionnaire, Care Burden Scale (CBS), and Social Support Scale and analyzed with SPSS21 using Pearson correlation coefficient, Chi-square, and Analysis of Variance (ANOVA) ($P=0.05$).

Results: The mean of the care burden of parents was 52.19 2.48 and the social support of them was higher than that (78.78 ±13.21). There was no significant correlation between social support and domains of general strain ($P=0.90$), disappointment ($P=0.52$), emotional involvement ($P=0.53$), environment ($P=0.95$), and isolation ($P=0.40$) of the care burden.

Conclusions: There was no correlation between social support and care burden in the parents of children with cancer. Other factors may be involved in care burden of the parents. More research is needed with more samples in the future.

Keywords: Social Support, Caregiver Burdens, Parents, Child, Cancer.

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Introduction

Cancer is a chronic disease that can affect almost all tissues of the body and has no age or sex restrictions. The disease is actually a genetic change in the cell that disrupts the natural order of cell division and differentiation (Parsa, 2012). Cancer is a common disease of the present century and the number of children with it is increasing (Ahmadi, Rassouli, Karami, Abasszadeh, & Poormansouri, 2018). Lifestyle changes, unhealthy diet and stressors have increased the incidence of this disease, especially in children. More than 16 million new patients are estimated by 2020 and are expected to cause 10 million deaths each year by 2020 (Ahmed, Shahid, & Gesy, 2015). It is one of the leading causes of child mortality in developing and developed countries (Panganiban-Corales & Medina, 2011). This disease is the second leading cause of death in children under 14 years old in Iran, accounting for 4% of children under 5 years old mortality and 13% of children aged 5-10 years (LOTFI, Vaziri, Arjmand, Mousavi, & Hashemieh, 2012). Over the past 30 years, the survival rate in children and adolescents with cancer has steadily improved and the cancer-specific death rate has decreased by more than 50% (Robison & Hudson, 2014). However, cancer is still one of the diseases that has a long and difficult treatment period and can cause many problems for families and family caregivers (Valizadeh, Joonbakhsh, & Pashaee, 2014).

Cancer is known as a crisis in a person's life (Naseri & Taleghani, 2018). In fact, cancer patients may face many problems in the physical, psychological, social, and economic fields (Abbasnezhad et al., 2015). Patients face many stressful situations during their illness that have important consequences for the patient and his family members (Naseri & Taleghani, 2018). When a disease such as cancer threatens a child's life, it affects mental and physical health and role-playing in family members (Kearney, Salley, & Muriel, 2015). Caring for children with cancer is an unpleasant and anxious experience for parents; which can lead to a burden of parental care. Care burden appears as physical, psychological, social or economic reactions that occur in the caregiver during care. It is defined and characterized as stress or negative experiences resulting from care in the caregiver (Ahmadi et al., 2018). The financial burden of childhood cancer may contribute to the distress that parents experience during and after treatment (Santos, Crespo, Canavarro, Alderfer, & Kazak, 2016). In caring of children with cancer, parents have to make changes in their lifestyle and roles, and because of their new circumstances, they may change their habits, including trying to increase income, trying to pass more time with their sick child, maintaining family relationships, and so on. Numerous factors such as duration of care, anxiety, average income, increase in clinical symptoms, type of disease, number of caregivers and social support affect the burden of care (Ahmadi et al., 2018). The burden of caring for family member decreases the child survival, recovering, and the beginning of treatment, but symptoms of distress persist for a long time in the parents. Research shows that children whose families have been more affected by the burden of care have shown less commitment to continuing and pursuing their patient treatment. These patients are more likely to experience symptoms more severely. The burden of chronic care profoundly reduces the quality of life of caring parents (Sullivan & Miller, 2015).

The crisis caused by leukemia and the child's hospitalization in the pediatric oncology ward is one of the main sources of stress and anxiety for the families of sick children, especially their mothers. Therefore, supporting and understanding the feelings and concerns of mothers is essential to provide better and higher quality care for the child (Pourmovahed & Roozbeh, 2016). Also, in recent years, there have been advances in the treatment of various cancers and a significant increase in the survival rate of children with the disease (Rodríguez-Sánchez et al., 2011). It is

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necessary to pay attention to the needs of mothers as caregivers of their children. In order for parents to be able to provide adequate care and support for the child, particular attention should be paid to both mothers and fathers and their specific caregiving roles (Leemann, Bergstraesser, Cignacco, & Zimmermann, 2020).

Social support is an important aspect of modern cancer care (Soltani & Khoshnood, 2021). It refers to various types of free social networking assistance, which may be formal or informal, and include physical and emotional support. Social support system is important protection factors for people experiencing stressful situations (Zhang, Zhao, Cao, & Ren, 2017). Social support is a concept that is derived from a network of people drawn from family, friends and community (Alsubaie, Stain, Webster, & Wadman, 2019). On the other hand, some researchers have defined social support as the amount of love, companionship, care, respect, attention and help received by an individual from other individuals or groups such as family members, friends, and others (Sarafino & Smith, 2014). When individuals perceive a high level of social support they tend to be healthier and better at coping with stress (Pilcher & Bryant, 2016).

Social support should be provided to the individual in different groups to be effective enough. Usually the social support group consists of family, treatment team and dependents (Espe-Sherwindt & Serrano, 2020). Each member of the family should pay attention to needs of the patients (Van Schoors et al., 2019). Results of studies have shown that people with spiritual well-being have a healthier lifestyle and are more satisfied with their lives (Tabei, Zarei, & Joulaei, 2016). Regarding parental support, other studies have been conducted with the aim of determining the nursing support system for mothers of hospitalized children with leukemia, determining the perceived support of mothers of children, nurses' supportive behaviors for mothers, and family caregiving burden of children with cancer (Khademi et al., 2019; Pourmovahed & Roozbeh, 2016).

Given that social support affects the quality of care provided to children with cancer, examining its impact on the burden of caring for parents can be effective in addressing their problems and the needs. Developing practical strategies to meet the needs of parents and reduce the burden of care is essential. Social support as a common factor in this study and other studies can play an important role in reducing the burden of care. Therefore, this study aimed to assess social support and caregiver burdens among parents of children with cancer referred to the clinic and pediatric oncology wards of Shahid Sadoughi Hospital in Yazd (Iran).

Methods

This was a cross-sectional, descriptive, and correlational study. The convenience sampling method was used with selecting 30 cases as a pilot. The correlation coefficient between social support and care burden was 0.22. Based on the correlation coefficient obtained and considering the 99% confidence level and 80% test power, 230 parents (115 mothers and 115 fathers) were selected.

Total sample size=N=[(Zα+Zβ)/C] 2+3=230

The standard normal deviate for α=Zα=2.5758

The standard normal deviate for β=Zβ=0.8416

C=0.5 * ln [(1+r)/(1-r)]=0.2237

The study population included parents of children with cancer referred to the clinic and pediatric oncology ward of Shahid Sadoughi Hospital in Yazd (city in the center of Iran) from March to August 2020. Researchers explained the purpose of the study to the patients' parents and asked them to answer the questionnaires. Inclusion criteria for parents were: having a child with cancer (age less than 15 years), parents not having chronic mental and physical diseases (based on self-report), having the ability to read and write, and the ability to answer questions. Inclusion criteria for children were: not having any other diseases, passage of at least two months

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since cancer diagnosis and follow-up treatment. Incomplete questionnaires and unwillingness to continue cooperation in the research were the exclusion criteria.

Data collection tools included demographic questionnaire, Caregiver Burden Scale (CBS) (Elmståhl, Malmberg, & Annerstedt, 1996) and Social Support Scale (Vaux et al., 1986) which were completed by the subjects.

The demographic questionnaire included parents' personal and the child's illness characteristics. Parental characteristics included parental age, marital status, parents' level of education, indigenousness, occupation, number of careers, ability to pay for treatment. Child characteristics included child age, child gender, and duration of cancer.

The Caregiver Burden Scale (CBS) was developed by Elmståhl et al. (Elmståhl et al., 1996)using factor analysis and designed to be valid regardless of diagnosis. It has been used to measure burden among caregivers to persons with various diagnoses (Elmståhl et al., 1996; Olai, Borgquist, & Svärdsudd, 2015), hemophilia (Lindvall et al., 2014), and traumatic brain injury (Caplan et al., 2015). The CBS consists of 22 items divided into five factors: general strain (8 items), disappointment (5 items), emotional involvement (3 items), environment (3 items) and isolation (3 items). Each item has four response alternatives: “not at all”, “seldom”, “sometimes” and “often”. A mean of all the answers comprises a score for the total burden. A higher score indicates a greater burden. In this study, the answers “not at all” and “seldom” were categorized as low burden and “sometimes” and “often” as high burden. A total burden index comprises the mean of all the 22 items and a higher score indicates a higher burden. The CBS has satisfactory validity and reliability with kappa values in the range of 0.89–1.0. This scale has been translated and validated by Farajzadeh et al. in Iran on 110 caregivers of patients with spinal cord injuries in 2017. Its content validity was 0.82 and its reliability was estimated as 0.74 to 0.9 based on Cronbach's alpha for all subscales (Farajzadeh, Akbarfahimi, Nedjat, Kohan, & Saberi, 2016). In our study, it was above 0.86.

The Social Support Scale was developed by Vaux et al. in 1986 based on Koob's definition of social support (Vaux et al., 1986). Social support refers to the level of love, assistance and attention of family members, friends and other people. This questionnaire has 23 items (one to five points) (Vaux et al., 1986). The results obtained with five samples of college students and five samples in communities showed a high reliability and validity of the scale. It had good internal sample consistency; the Cronbach’s alpha was 0.9 for the sample of college students; The alpha was 0.9 for friends and 0.81 for family in the community sample. It also showed stability after a six-week interval in a sample of college students (r=0.8 and r=0.71 for the subscales family and friends). In this paper, the scale also showed good internal consistency, with a Cronbach’s alpha=0.86. In the study by Khabaz et al., the calculated alpha coefficient for this questionnaire was 0.74 (Khabaz, Behjati, & Naseri, 2012; Vaux et al., 1986). Cronbach’s alpha in our study was 0.84.

Data were analyzed statistically using SPSS21 with 95 confidence level. Descriptive statistics were used to describe the demographic variables. The Chi-square tests were used to examine the relationship between the studied variables and demographic variables. The Pearson Correlation Coefficient test was used to determine the relationship based on the normal distribution of data. Analysis of Variance (ANOVA) was used for comparison of the means ($P<0.05$).

The study was approved by the institutional review board with the ethics code: IR.SSU.MEDICINE.REC.1398.042. Informed written consent was obtained from all participants before their enrollments in this study.

Results

The mean age of mothers was 34.30±6.59 and the mean age of fathers was 39.04± 6.99 years. Besides, 66.1% of parents were native to Yazd. Sixty

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children (52.2%) were boys and 55 children (47.8%) were girls. The majority of children, 57 persons (49.6%), had two caregivers. Sixty two children (53.9%) were cared for more by their mothers. For 12 children (10.5%), their parents took care of them. The majority of children, 82 persons (71.3%), had ALL (Acute Lymphocytic Leukemia). The mean age of children was 65.29±37.98 months (max: 131). The mean number of hospitalizations of the child was 8.56±8.04 times (max: 17), and the average length of hospitalization of the child was 32 ±39.42 days (max: 65). Also, the mean score of parental care-giving burden according to the types of child treatment (chemotherapy and chemotherapy with radiotherapy) were significantly different (P=0.003). Table 1 shows the characteristics of parents.

There was no significant relationship between mothers' and fathers' age with social support score (P=0.297 and P=0.667, respectively). It did not differ significantly according to the level of education of mothers and fathers (P>0.05). The highest mean score of social support belonged to housewife mothers (79.57±13.46) and self-employed fathers (79.65±13.78). The average score of social support for married mothers was higher than divorced mothers (79.15±13.29 and 63.50±12.32) (P=0.04). There was no significant difference between the mean score of social support between natives and non-natives of Yazd using Chi-square test (P>0.05). Also, there was no significant correlation between social support and the scores of general strain, disappointment, isolation, emotional involvement and environment (P>0.05). Also, no significant correlation was observed between care-giving burden score and social support score (P=0.34). (Table 2)

There was no significant correlation between the child's age, duration of illness, the length of hospital stay, and mean score of care-giving burden (P>0.05), but there was a significant correlation between the number of hospitalizations and the mean score of care-giving burden (P=0.02). This correlation was positive and direct (r=0.278) (Table 3).

Table 1. Demographic and socio-economic characteristics of the study population

Variable	Category	Mothers n(%)	Fathers n (%)	P-value
Education	-Primary and secondary schools -Diploma and associate degree -Bachelor's degree and higher	38(33.1) 48(41.7) 29(25.2)	35(30.5) 38(33) 42(36.5)	0.53*
Occupation	-Housekeeper -Employee -Worker -Self-employed	74(64.3) 41(35.7) 0(0) 0(0)	0(0) 30(26.1) 62(53.9) 23(20)	0.54*
Affordability of the hospital costs	Yes No	58(25.2) 57(24.8)	58(25.2) 57(24.8)	0.25*
Being a native	Yes No	76(33) 39(17)	76(33) 39(17)	0.70*

* Chi-square

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Table 2. Pearson Correlation Coefficient between the mean score of care-giving burden and its indices with the mean score of social support in the studied parents

	General strain		**Isolation**		**Disappointment**		**Emotional involvement**		**Environment**		**Care-giving burden**	
	r	**P-value**	**r**	**P-value**	**r**	**P-value**	**r**	**P-value**	**r**	**P-value**	**r**	**P-value**
Social support	-0.013	0.90	-0.067	0. 4	-0.069	0.52	-0.065	0.53	0.007	0.95	-0.107	0.34

Table 3. The Pearson Correlation coefficient of parental care-giving burden with children's age, number of hospitalizations, duration of illness, and length of hospitalization

	Mean± SD	**r**	**P-value**
Children age (months)	65.29±37.98	0.062	0.566
The duration of the disease (day)	445.37±353.01	0.014	0.898
Number of hospitalizations	8.56±8.04	0.278	0.021
The length of hospital stay (day)	31.99±39.42	0.187	0.109

Discussion

The aim of this study was to determine the effect of social support on the care-giving burden of parents of children with cancer. The results showed that the parental care-giving burden was moderate. In a similar study, it was found that the burden of parental care was mild (Kahriman & Zaybak, 2015), which is not consistent with the results of this study, perhaps due to cultural differences between variant communities. One explanation for difference in caregiver burden could be duration of the disease. Caring for a sick child is one of the responsibilities of parents and they consider themselves obliged to take good care of their child in the hospital as well as at home, without knowing the burden of care and its meaning. Parents' experiences in this regard indicate their high distress. Diagnosis of cancer, even in developed countries, is very stressful for both the patient, the parents, and caregivers (Kahriman & Zaybak, 2015).

In this study, the mean score of care-giving burden was significant according to the type of treatment of the child, so that the score of care-giving burden for children with chemotherapy was lower than the score of care-giving burden for children with chemotherapy and radiation therapy. The results of the care-giving burden obtained from our study are similar to the research conducted by Turkoglu & Kilic that the higher the number of treatments, the higher the care-giving burden of patients (Turkoglu & Kilic, 2012). One reason for this similarity could be the treatments performed by them.

In general, it can be said that the perceived care-giving burden in parents of children with cancer depends on the degree of dependence of parents and children. More dependent caregivers have a higher care-giving burden. It can be said that when patients' dependence increases, they demand more help in even the simplest tasks such as eating, drinking, and bathing, which ultimately creates more care-giving burden in caregivers. The patient's greater dependence on the caregiver increases the burden of care perceived by him or her. In this study, in general, no significant correlation was observed between the care-giving burden score and the social support score. This finding is consistent with the results of one study (Kahriman & Zaybak, 2015; Zaybak, Güneş, İsmailoğlu, & Ülker, 2012).

Social relationships play an important role in helping people cope with life's challenges and resist the negative effects of stress. In the present study, the score of social support was above average. Informal social support is closely related to the caregiver burden. Caregivers with little social support experience higher levels of care-giving burden. There is no doubt that family support plays a vital role in helping individuals cope with stressful or worrying situations (Cooper, Powe, & Smith, 2013).

In the present study, social support of parents was not effective in the care-giving burden. In fact, there was no significant correlation between social support and the scores of all domains of care-giving burden. In this regard, it can be said that the traditional social structure in Iran can influence this result. In this structure, the concept of family and cooperation between family members and even relatives are of great value and are considered a lifelong experience. Excessive social support may cause parents to sometimes try to control themselves and don't let others to intervene, which in turn, has a negative effect on them and increases stress levels (Kahriman & Zaybak, 2015). Another justification for confirming this finding is that perhaps receiving support from a particular friend or person can have a more calming effect and feel less care-giving burden. Barber in his study showed that social support from friends has a positive effect on increasing the motivation of cancer care providers (Barber, 2013). It is clear that people are closer to their peers and friends emotionally. In such situations, family support has less of an impact on the care-giving burden. Therefore, in addition to meeting the supportive needs of caregivers by their families, friends, partners, or special individuals, their needs need to be met systematically by the relevant institutions to minimize the negative effects of the care-giving burden.

In the present study, a direct and significant correlation was observed between the number of hospitalizations of the child, the length of hospitalization, and the mean score of parental care-giving burden. Given all these findings, in order for parents not to suffer physiologically or psychologically due to excessive and long-term care, it is necessary to be aware of the potential care-giving burden and its consequences, and to closely monitor the care-giving process to deal with it and adapt. During this process, evaluating social support systems in coordination with caregivers may have effective results on their awareness. It is also necessary to provide professional advice on the issue of social support and encourage parents to receive such services to reduce their care-giving burden. Healthcare workers should pay more attention to caregivers and help them to cope with their difficulties.

This is the first cross-sectional descriptive study on care-giving burden among parents of children with cancer in Yazd. Another strong point is that the majority of the parents of children with cancer referred to Oncology Clinic and Ward in Yazd Shahid Sadoughi Hospital (Iran). Sampling of this study was done during the corona outbreak. We encountered many problems to access the parents under study (due to the nature of the disease, relocation of the oncology ward and its allocation to patients with COVID-19); therefore, the time of our research was prolonged. Another limitation was less access to the fathers, which was solved with continuous follow-up. Also, this study was conducted in a province (Yazd) in the center of Iran and its results can’t be generalized to other provinces with many cultural differences.

It is suggested that future research focus more on plans to reduce the care-giving burden of parents of children with cancer and other chronic diseases. Family-centered care is also important. It is suggested that a study be conducted to investigate the effect of family-centered care on the care-giving burden of parents of children with cancer. It is recommended that managers and care team pay attention to patients' families and establish units to educate families to reduce the care-giving burden and support them.

Conclusion

There was no correlation between social support and care burden in the parents of children with cancer. Other factors may be involved in care burden of the parents. More research is needed with more samples in the future. Other similar studies can focus on other family members of the children with cancer. Further studies are needed to

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find factors for decreasing the parental care-giving burden.

Conflict of Interest

The authors declare that they have no conflicts of interest.

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Authors' Contribution

Conceptualization, B.R.; Methodology, M.N.; Formal Analysis, M.S.G.; Investigation, Z.P.;

Writing, Reviewing, & Editing, Z.P.; Supervision, B.R.; Writing, Original Draft, Z.P. All authors read and approved the final manuscript and are responsible for any question related to the article.

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