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Caring power of mothers who have a child with cancer and its predictors

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Abstract

Background: Attention to the family care provider needs and their caring power is essential. Since mothers are considered as the child's main care provider, this study aimed to determine the caring power and its predictors among mothers of children with cancer.

Materials and Methods: In this descriptive-correlational study, 196 mothers who had a child with cancer were selected through purposive sampling. The data were collected using two questionnaires, namely demographics questionnaire and the care power of the care providers of cancer patient questionnaire. The data were analyzed using SPSS 19 and running descriptive statistics and regression analysis.

Results: The highest average score belonged to dimensions of "effective role play" (44.62 ± 5.28) and "trust" (14 ± 1.67), and the lowest ones respectively belonged to dimensions of "fatigue and resignation" (22.38 ± 6.33), "awareness" (8.46 ± 2.70), and "uncertainty" (12.38 ± 3.50). In addition, variables of educational level ($p < 0.001$), adequacy of family income ($p < 0.001$), and duration of illness (p□0.29) were found as predictors of caring power.

Conclusion: The results of this study showed that the caring power of mothers with a child with cancer is favorable. High trust and effective role-play reduced fatigue and resignation of mothers, and low awareness about the provision of care caused uncertainty affecting negatively the care power. In addition, the adequacy of family income, the high level of mother's education, and the reduction in the duration of the disease had a direct impact on care power.

Keyword: Caregivers, Child, Mothers, Neoplasm, Power

Introduction

Cancer is one of the reasons of death in children and adolescent in the world (1). Annually, three hundreds thousands children get cancer (2). According to Globacon's statistics in Iran, 1,567 cases per year are reported, of which 1037 lead to death. Cancer is considered as the second reason of death in children under 14 years old (3). Cancer in Iran is responsible for the mortality of 4% of childern aged less than 5 years old and 13% of children aged 5 to 15 years (4).

The cancer-related challenges for the family and the uncertain prognosis of this disease distinguish it from other chronic children's diseases (5). Caring for a cancer patient, especially in advanced stages and observing his/her pain and suffering make family care-givers experience a great deal of tension (6). However, in developing countries, the national plans to support family care-givers have major deficiencies and pose serious challenges (7). Despite the effectiveness of this type of care, imposing the care burden to the family, without giving them serious assistance, will have adverse effects on the family system and on care providers' physical, mental, social, and spiritual health (8, 9).

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Empowerment, as the conceptual framework of the present study, forms the main framework of health promotion programs (10). It is a dynamic process which focuses on individuals' abilities and their care capabilities and requires considering the family and its needs as the center and the core of care, which is to be designed in accordance with the care-giver's conditions. In order to achieve optimal care outcomes, the empowerment method should be selected and implemented according to the care-giver's individual conditions, experiences, social status, cultural level, and beliefs on one hand, and determining his/her caring power on the other hand (11, 12).

Obviously, mismatch between the mother's demands and her ability to act as the primary care-giver of the child with cancer causes problems that lead to her instability and uncertainty in dealing with the child's illness (13) and influences her quality of life (14). Studies have shown that many mothers suffer from mental health problems such as depression, anxiety, and chronic sadness associated with their children's cancers (4, 15).

The mental health of care givers is of great importance (16) and the family's role is crucial in maintaining and improving the quality of life for children with cancer (9). Since family care givers carry out 70-80% of the care for cancer patients, they help reduce the cost imposed upon the health system significantly; therefore, family care givers are mostly regarded as a hidden care potential (17).

Accordingly, the empowerment of the mothers who have a child with cancer, as one of the nurses' tasks (18), can play an important role in reducing stress and improving the quality of life, as well as supporting and helping them strive to preserve individual and family life and control negative feelings and the fears about the child's disease (19, 20). The first step to empower the mothers of the children with cancer is recognizing and paying attention to the needs of these mothers (19, 21) and in other words, examining their care power. Care power is defined as possessing the necessary features and skills in order to care for others (22); it represents the attitude, knowledge and behavior of parents in care giving to their child (20). Therefore, it can be concluded that in order to achieve the best outcomes of caring for the children with cancer, paying attention to the parents' care power is very important. The systematic review results of Bee et al. (2009) have highlighted the importance of providing accurate care information in adapting to the conditions and contributing to informed decision-making in relation to patient care (23).

Informal caregivers, without adequate information, will be incapable of decision making and adapting to care challenges; therefore, they use trial and error, which itself increases anxiety in them. The family's care power is influenced by the factors that can affect the patient's recovery process and the health of family care givers (24).

In other words, caring power can be influenced by some of the characteristics of the care provider, and identifying these features seems necessary in order to improve care power.

Therefore, by determining the care power of the mothers of the children with cancer and their needs in this area (5), as well as identifying the factors that are somehow considered as caring power predictors affecting their care power, it will be possible to use interventions to empower them in caring for a child with cancer (25).

Since determining the mother's care power is considered as a prerequisite for her empowerment in caring for a child with cancer, this study was conducted with the purpose of determining the care power and its predictive factors among mothers of children with cancer.

Materials and Methods

The present study was a descriptive-correlational type conducted from

February to May 2018. The study population included the mothers who had a child with cancer hospitalized in one of the oncology wards of Mofid Hospital, Children's Medical Center, or Ali-Asghar Hospital. The participants were selected through purposive sampling according to defined inclusion criteria. The inclusion criteria were as follows: mothers needed to be the main care givers of the child with cancer and have the ability to read, write, comprehend and speak Persian. They were also supposed not to have any history of psychological disorders or hospitalization in mental wards. In addition, it was necessary for the child to have been diagnosed with cancer at least 6 months prior to the study, and to be in the age range of 1-17.

The minimum required sample size was estimated to be 171 people. Considering the probable loss of samples, 196 mothers of the child with cancer were examined.

The tools used in this study included two questionnaires. The first questionnaire consisted of two parts: "the mother’s demographic information" including age, marital status, education, the number of children, the spouse’s occupation, the mother's occupation, the adequacy of the family’s income, and their residential place. The "clinical features of the child" questionnaire included cancer type, disease duration, and the type of treatment used for the child.

The second questionnaire was "Family Caregiver Empowerment for Cancer Patient questionnaire" designed and underwent a psychometric test by Nemati et al in 2017, including 29 items with five sub-scales of "Effective role play", "Trust", "Uncertainty" "Fatigue and Resignation" and "Awareness." The caregivers’ responses were rated on a five-point Likert scale, from the score of 1 for “Never” to the score of 5 for “always”. This tool was given to five mothers who had a child with cancer in order to examine the comprehensibility and the easiness of responding to the terms of the tool. In order to determine the reliability of the tool, two methods of determining internal consistency and stability were used. In order to examine the internal consistency, the questionnaires were handed to 20 of the eligible mothers who met the research sample criteria, and after completing them, the Cronbach's alpha coefficient was calculated for the whole tool as well as each of its sub-scales.

The Cronbach's alpha was found to be 0.75 for the dimension of "Effective Role Play", 0.08 for "Fatigue and Resignation", 0.72 for “Trust”, 0.69 for “Uncertainty", 0.67 for "Awareness", and the Cronbach's alpha for the whole tool was found to be 0.7. Moreover, in order to calculate the reliability of stability, the questionnaires were given to 20 mothers of the children with cancer twice with a 10-day interval. The Interclass Correlation Coefficient (ICC) was calculated 0.75.

In this research, at first, consent was obtained for conducting the research and a full explanation on the questionnaire was given to the mothers, and they were informed that the information in the questionnaires would be confidential. The approximate time to complete each questionnaire was estimated to be about 20 minutes. Then, the research tools were given to mothers by the first researcher. Sampling was done in morning and afternoon shifts. In order to maintain the comfort and tranquility of the mother and the child, the mothers whose children were hospitalized in the ward were given 24 hours after the distribution of the questionnaires to complete them. However, due to lack of access to the mothers of the children referring to the clinic, the questionnaires were collected in less than one hour after the distribution.

Statistical Analysis

The software used for data analysis was SPSS (version 19), and descriptive statistics and regression analysis methods were used to analyze the data.

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Results

This study was performed on 196 mothers who had a child with cancer. The results showed that the average age of the mothers was 34.53 years old and the duration of the disease was 17.87 months. According to the results, the maximum duration of the disease was 25 to 36 months and the minimum duration of the disease was 6 to 12 months. Table 1 shows the care power scores of the mothers participating in the study based on the individual and social characteristics of the mother and the child.

The variables of education, the duration of the child's illness, the father's occupation, the mother's occupation, income adequacy, the current residential place, and the birth rank of the sick child were selected and included in the regression model through step-by-step method. The selection criteria was the existence of a significant correlation between the considered variable and the mother's care power variable, or creating a significant difference in the care power score among the different classes of considered variables at the minimum confidence level of 80%. The results of the regression analysis showed that among the above-mentioned variables, only the three variables of income adequacy, education, and the duration of the child's disease were significant and the other variables were excluded from the model.

According to Table II, the level and the dimensions of the care power of the mothers who had a child with cancer. According to this Table, the highest level of care power belonged to the dimension of trust (14 ± 1.67) and the lowest to the dimensions of fatigue and resignation (22.38 ± 6.33), and awareness (8.46 ± 2.70), respectively. The regression test was used to determine the care power predictive variables among these mothers. To this end, at first, the difference in the mothers' care power scores in different classes of the demographic characteristics of the mother and the child was assessed using independent t-test and one-way ANOVA tests (Table I). Regarding the results given in Table I, the variables that had higher correlation possibility with the mother's care power were introduced into the regression model. For this purpose, the variables of education, the duration of the child's illness, the father's occupation, the mother's occupation, income adequacy, current residential place, and the birth rank of the sick child were selected and introduced into the regression model through the stepwise method. The results of step-by-step regression are shown in Table III. Regression results indicated that among the mentioned variables, only three variables of income adequacy, education, and the duration of the child's disease were significant; therefore, other variables were excluded from the model. According to Table III, three variables of income adequacy, education, and the duration of the child's disease had the highest predictive power of the mother's care power, accounting for 18.4% of total changes in the mother's care power.

Table I: The mothers' caring power score based on the demographic characteristics of the mother and the child

		Number N	The mother's caring power score	p_{value}	The type of the test
The Child's gender	girl	86	102.30 (9.82)	P=0.83 t=0.21	**t-test**
	boy	110	101.73 (10.32)		
Education	Illiterate and elementary	26	105.85 (9.14)	p< 0.001 F=10.72	**ANOVA**
	Middle school degree	36	105.14 (9.6)		
	High school diploma	80	103.13 (9.27)		
	University degree	54	95.83 (9.6)		
Marital status	married	188	101.70 (10.12)	P=0.28 t=-1.07	**t-test**
	single	8	105.63 (9.2)		
The sick child's birth rank	the first	98	100.83 (10.15)	p< 0.001 F=12.3	**ANOVA**
	the second	68	102.07 (8.82)		
	The third and on	30	104.77 (12.19)		
The father's occupation	employee	52	99.60 (9.2)	p< 0.015 F=4.25	**ANOVA**
	Self-employed	108	101.63 (10.3)		
	Retired or jobless	36	105.83 (9.84)		
The mother's occupation	employed	18	94.56 (8.30)	p= 0.001 t= -3.30	**t-test**
	housewife	178	102.60 (9.98)		
Income adequacy	yes	51	95.96 (8.61)	p< 0.001 t= -5.16	**t-test**
	no	145	103.94 (9.78)		
The duration of the child's illness	6-12 months	104	100.82 (9.28)	p= 0.29 F=1.24	**ANOVA**
	13-24 months	52	103.35 (10.94)		
	More than 25 months	40	102.65 (10.91)		
The child's type of illness	leukemia	104	102.23 (10.02)	p= 0.58 t= 0.54	**t-test**
	Others Blastoma Sarcoma, lymphoma,…)	92	101.45 (10.22)		
Treatment stage	chemotherapy	192	101.98 (10.16)	p= 0.24 t= 1.17	**t-test**
	Radiotherapy, surgery, Bone marrow transplant	4	96 (3.46)		
The current residential place	Owns one	124	101.02 (10.17)	p= 0.12 t= -1.53	**t-test**
	Doesn't own any	72	103.31 (9.87)		

Table II: Level and the dimensions of the caring power of the mothers of children with cancer

		Score range	The mothers' score (SD±μ)	The average score in each sub-scale
Caring power	effective role play	11-55	44.62 ± 5.28	4.06
	Fatigue and Resignation	8-40	22.38 ± 6.33	2.80
	trust	3-15	14 ± 1.67	4.67
	uncertainty	4-20	12.38 ± 3.50	3.10
	awareness	3-15	8.46 ± 2.70	2.82
	Total score	29-145	101.86 ± 10.10	3.51

Table III: Regression analysis of predictive caring power variables

	predictive variable	Beta coefficient	P	F	R^2
The first step	Income adequacy	0.347	< 0.001	26.63	0.116
The second step	Income adequacy	0.268	< 0.001	20.70	0.168
	The level of education	-0.249	< 0.001		
The third step	Income adequacy	0.278	< 0.001	15.66	0.184
	The level of education	-0.240	0.001		
	The duration of the child's disease	0.142	0.03		

Discussion

Caring for a patient with cancer, especially in advanced stages, and observing the patient's pain and suffering causes a lot of stress for family care givers (22). Cancer children's mothers are more likely to face challenges because of the nature of cancer, which is associated with a higher risk of death, recurrence, and hospitalization (5) and awareness of mother's caring power can be helpful in care planning (22). Therefore, the present study was conducted with the aim of assessing the caring power and the predictors of the caring power among this population.

The results this study showed that, among five dimensions of mothers' caring power, the dimension of "Trust" obtained the highest score, which was considered as an expected finding. Trust and faith in God is an expression of the inner spirituality of individuals that creates a great power in humans, which results in the promotion of the quality of life and peace (26, 27).

Spiritual and religious beliefs help mothers imagine a meaningful framework for the suffering caused by the circumstances, making it easier for them to accept the conditions (28).

This trust is a reflection of the spiritual tendencies in the thoughts, beliefs, and behavior of the individual that can affect one's deeds in the care setting (29). Religion and spirituality are known as a comprehensive coping strategy in dealing with the tensions resulting from exposure to refractory diseases such as cancer (28, 29). This strategy is more manifested in countries such as Iran with a more religious background. In this regard, the results of studies conducted in this country indicate that many family care givers of

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cancer patients, including mothers, are using this approach a lot.

Another dimension of caring power is "to play an effective role", which gained a relatively high mean score. Caring for a person with cancer not only is costly and takes a lot of time and energy, but also creates conditions that it is very emotionally demanding for a caregiver (30). During childhood cancer process, the family is at risk of psychological and mental problems (4). It affects the communication patterns of caregivers, their job performance, and their social roles (31). After initial diagnosis of their child's disease, the families try to adapt their child's care demands to the daily responsibilities of the family and try to normalize the conditions. Some examples of these efforts include the acceptance of a child's illness, considering the possibility of the family's being harmed due to the child's illness, their redefining an ordinary family, and focusing on the usual dimensions of life and social engagements (5).

Considering uncertainty dimension, the findings of this study showed that this dimension requires more attention on the part of care providers, which is in line with findings of studies conducted by Dumont et al., (2008) and Harrow et al., (2008) (32, 33). Uncertainty means understanding the complexity of a disease, and being concerned about its uncertain future and consequents on the family life of the care giver. It is considered as one of the most important psychological stressors that affect one's coping behaviors and abilities (34) which not only can affect the outcomes of the disease and the individual's psychological adaptation, but also diminishes the care givers' daily activities and their quality of life (35).

The dimension of awareness had lower average score than most of the dimensions of caring power, which is consistent with the results of other research, revealing that lack of information and skills along with the inaccurate understanding of available information is a major challenge in care provision (22).

Without adequate information, informal caregivers feel that the conditions are out of their control, thus they become incapable of making decisions and adapting to care provision challenges. As a result, they use trial and error, which itself leads to increased anxiety in them and it may prevent them from succeeding in providing the patient with support and care (23, 36). The lack of information on the process of the disease and its treatment and prognosis, the lack of prior experience, the lack of interest in learning about this subject, and cognitive impairment or the lack of familiarity with the information sources on the disease are considered as important challenges for the mothers caring for children with cancer (37). Most of the time, the lack of knowledge is the most important reason behind their indecisiveness; therefore, the knowledge and the skills related to care are among the critical factors in patient care (22).

The dimension of "Fatigue and Resignation" was found to possess a low average score among mothers participating in the study, which was an unexpected finding according to the nature of cancer. Researches, mainly on the family care givers of chronic patients, indicate that care givers' stress is one of the causes of fatigue (38), and "Failure and Resignation" is the outcome of the care burden of the care giver, which can influence the caregiver's caring power, leading to indifference about continuing care provision for the patient (39). The reason is that the care burden makes them feel left alone with the heavy responsibility of patient care (40).

Since the average score of trust was high, but that of fatigue was low in the present study, it can be concluded that, in line with the results of research by Nikfarid et al (2018), mothers who have a child with cancer mostly use spiritual and religious coping approaches to face the existing challenges (4). Therefore, loneliness is less

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likely to be seen in the mothers; therefore, they suffer from fatigue and resignation less.

Given that the identification of factors affecting care power is considered as a step toward promoting this variable, some of the predictors of the mothers' caring power were studied in this study, too. Among mothers' demographic variables, education, the family's income level, and the duration of the disease were in a correlation with their caring power.

Some studies have shown that age, sex, socioeconomic status, and education are among factors that can influence the responses of family caregivers to the new care role (41). In the present study, only two variables of income and mother's education were recognized as influential variables.

The results a previous study has shown that mothers' low educational level can affect their information and knowledge about their caring role (42).

Moreover, parents of children with cancer who are more educated tend to use problem-based coping strategies such as "confronting", and "responsibility" more often (43, 44). Continuous stress and burnout caused by the child's illness and financial problems can reduce the care power of care givers (44). Economic challenges caused by care burden, frequent commutes from remote areas to hospitals, financial problems due to the chronic illness, missing out on employment opportunities, and lower income are among the factors that affect the economic situation and the family's income and consequently can decrease the family's caring power, especially mother's (37). Although, , it seems that "health sector evolution program" in Iran with the main goal of financial support of patients with major illnesses can partly improve the declined care power of families of children with cancer resulted from financial problems (5).

The nature of cancer, considering long-term care and the pressures associated with it, causes many difficulties for the family and can interfere with their care performance (22). The result of the present study showed a significant correlation between the duration of child's illness and mother's care power. The findings of some of the other studies also showed the level of care stress in various stages of the disease in families with cancer patients. For example, Schumacher et al., have shown that care givers undergo more stress at the first stages of the disease. However, due to the chronic nature of the disease and its treatment process, they gradually adapt to the existing conditions, and even at the recurrence stages of the disease, they experience less care pressure (45). The existence of the disease and its continuation make families apply changes in their performance areas; since in some cases, the strategies that they use to confront and control the disease are either ineffective or carried out in an improper manner (46), reducing their caring power over time, from the onset of the disease on.

Conclusion

The results of this study showed that the caring power of mothers with a child with cancer is favorable. In fact, high trust and the effective role play of mothers reduced their fatigue and resignation. In addition, low awareness of mothers emphasized the need for training mothers to care of their sick children. Since low mother's awareness can cause uncertainty in care, increasing awareness can be effective in care power. In this study, demographic variables and patient clinical variables were reportes as caring power predictive variables. Due to growing incidence of cancer in our country and the necessity of empowerment of patients and caregivers, it is needed to consider factors affecting mother's caring power and dimensions of their caring power and also to implement effective intervention to enhance the various aspects of mother's caring power.

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This article is part of a MSc nursing thesis and it is approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences (IR.SBMU.PHNM.1396.845). The study was then conducted upon obtaining a letter of introduction from the university and obtaining permissions from the hospitals. Informed written consents were also obtained from the participants once they were ensured about the confidentiality of their data throughout the study and in the publication of the results as well as about their right to withdraw from the study.

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Conflict of interest

The authors declare that there are no conflicts of interest regarding publication of this article.

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