

The effect of family-centered care on self-efficacy and hope in parents of children with cancer

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Abstract

Introduction: Cancer is one of the most important diseases in children, and despite many advances in the field of treatment, this disease is still one of the most difficult chronic diseases in this period. Families want to help care for the child, but parents need the guidance, information, and full support of caregivers. Also, hidden expectations and uncertain roles are stressful for families. Thus, this study was conducted to evaluate the effect of family-centered care on self-efficacy and hope in parents of children with cancer.

Methods: First, 54 parents of children with cancer were selected for this study, and after obtaining the necessary permits, the cases were randomly divided into two experimental and control groups. Then, after identifying the subjects in the experimental and control groups, the experimental group was subjected to the family-centered model. Meanwhile, the control group received routine care and after completing the training, self-efficacy and hope questionnaires were completed by the cases of the experimental and control groups.

Analysis: The intervention and control groups were not significantly different in terms of the results of the self-efficacy scale before the intervention ($p = 0.096$) and according to the available data, there was not enough evidence to reject the null hypothesis. However, after the intervention in both study groups, the data were at a significant level according to the test statistics ($p < 0.001$). Regarding hope questionnaires and available data, it was found that before the intervention, the two control and intervention groups were not significantly different at the alpha level of 5% ($p = 0.456$), but after the intervention, the data of the two groups were significantly different and a positive effect was observed ($p < 0.001$).

Conclusion: In this study, it was observed that family-centered care leads to improved self-efficacy and hope in parents of children with cancer. Also, family-centered care may affect the psychological functioning of parents, regardless of treatment status or patient age. In general, according to our findings, it is recommended that family-centered care be provided in pediatric oncology wards.

Introduction

Cancer is a chronic life-threatening disease and a serious health problem worldwide, and it is one of the leading causes of death in children and adolescents (1). Cancer is one of the most difficult chronic diseases of childhood and despite significant progress in the field of cancer treatment over the last three decades, this disease is still considered one of the most influential chronic diseases in children. The sudden and stressful onset of cancer, the aggressive and long-term treatment of the disease, and the immediate and lasting complications of the disease and treatment have

given it a special face (2, 3). Childhood cancer is diagnosed under the age of 15. About 300,000 children are diagnosed with cancer each year, affecting families and communities around the world. With access to adequate care, more than 80% of children with cancer can survive and live a healthy life. However, many children in low- and middle-income countries do not receive adequate care, and as a result, more than 90% of deaths due to childhood cancer occur in low-income countries. According to the World Health Organization (WHO), every year, 40 out of every one million children are diagnosed with cancer before the age of 15. Annually, 2000 new cancer cases are reported in children (4). Also, cancer is the cause of about 4% of deaths in children under 5 years of age in Iran (5). The survival rate of cancer patients has increased over the last four decades, but this increase in the chances of survival is associated with invasive treatments, chemotherapy, frequent hospitalizations, and long-term and precise care (6). Pediatric cancer is a major challenge for the patient, family, and healthcare team. In this regard, they are looking for different solutions for challenges such as anxiety, frustration, pain, and sorrow (7). Parents of children with cancer suffer from many psychological disorders (8), which can have negative impacts on their quality of life. Studies conducted in our country also show the low quality of life in these children. Since the family is considered the primary caregiver of the child, the psychological, economic, and social pressures of the child's disease have a profound effect on family life and overshadow all aspects of the life and health of the family members (9). From the beginning of diagnosis, cancer strongly affects the physical, social, psychological, and spiritual dimensions of patients and their caregivers and puts them in a challenging situation. In particular, mothers of children with cancer have a very disturbing experience in the family. They are shocked and have to live with constant pressure. Their child's disease affects the family and as a result, their quality-of-life decreases (10). Parents are constantly rebuilding their roles, functions, and interactive and communication patterns inside and outside the family, and they also have many caring responsibilities due to their membership in the treatment team (11). From the onset of symptoms and diagnosis, they endure countless emotional and psychological pressures. In the process of care, they may face many physical, social, and economic problems, and their family life, marriage, work, health, and social life may be affected by the disease and the care of a child with cancer. Research has shown that having a child with cancer can lead to emotional instability, insecurity, and tension among family members, especially parents (12). Persistence of anxiety, confusion, and caring responsibilities affect the performance of parents during treatment and child care (13). The importance of this issue is such that parental anxiety has been reported as a predictive factor in the quality of life and physical, mental, and social status of the child (13). Anxiety can disrupt the daily life of vulnerable parents and may affect the child's coping abilities. It is recommended that parents and caregivers take appropriate interventions to optimize the well-being of family members and children and to assess their mental health needs early and continuously (14). 44 percent of parents have difficulty recognizing their child's needs regardless of the time of diagnosis, the number of days hospitalized, and the age of their child (15). Most of the parents' needs are informational, psychosocial, physical, practical, and spiritual. Also, parents have high expectations of nurses as the primary source of support (16). Children and their caregivers are reliable and important sources for setting therapeutic goals. Basic human needs, including communication, competence (self-efficacy), independence, and meaningful personal orientation, should be considered in prioritizing goals for intervention (17). A study found that parents of children with non-acute illnesses maintained positive self-efficacy and became more active in health care with higher tolerance against uncertainty, but these are associated with a high level of emotional costs for parents. As the psychological needs of the parents may not be obvious, these issues should be addressed, and the necessary support should be provided (18). The lower self-efficacy in mothers leads to more significant pain in the patients (19). Also, the level of the mother's hope is associated with the child's level of hope (20). Mothers of children with cancer need hope to use positive thinking and pre-treatment. Hope during the period of illness is essential for recovery through treatment and is the main source for enduring the process of caring for patients (21). Parents' hope scores are predicted by self-efficacy and depression. These results have practical implications for physicians seeking to increase the hope of children with chronic diseases, and it is suggested that hope-based interventions should be tailored to the individual and the time of onset of the disease. (22) Previous studies have shown that self-efficacy and hope are associated with post-traumatic growth (23). Hope is defined as the cognitive evaluation of information about future goals and it has a motivational quality that may flow depending on the situation (24-26). Family-centered care (FCC) is a method of health care delivery that emphasizes partnerships between providers, patients, and families (27). In these situations, families want to help care for the child, but parents need the guidance, information, and full support of nurses. Hidden expectations and uncertain roles are stressful for families. Nurses need skills training, adequate resources, and managerial support to be able to appropriately meet the needs of families, have real cooperation, and provide family-centered care (28). Few studies have been conducted on the impact of the family-centered care model on caregivers and family members of children with chronic diseases, and

most of these studies have focused on program ambiguity for issues related to the outcomes of children with chronic illness or cancer. (11, 29-33) Thus, this study was conducted to evaluate the effect of family-centered care on self-efficacy and hope in parents of children with cancer.

Methods

First, after obtaining the necessary permits, the cases were randomly divided into two experimental and control groups. The ethical code of this research was IR.IUMS.REC.1399.994 and the code was IRCT20141216020344N3.

A total of 54 parents of children with cancer were studied. Then, after identifying the subjects in the experimental and control groups, the experimental group underwent a family-centered model, while the control group received routine care. After the intervention and one month later, all subjects completed the self-efficacy and hope questionnaires. Finally, the data obtained from the questionnaires were collected and analyzed. Inclusion criteria included parents of children aged 6 to 12 years with cancer, no history of mental illnesses in parents according to self-report, knowledge of the type of child's disease, lack of stressful events other than the child's disease during the past year, not attending similar training sessions and classes, hospitalization and presence of the child for at least 5 days in the ward, and not caring for another patient at home. The family-centered model was implemented in four stages of threat perception, self-efficacy, educational participation, and evaluation, and the training was performed during four sessions of 20 to 40 minutes for the intervention group; The control group received only routine ward care. According to the family-centered model, the first step in the intervention phase is threat perception, in which parental knowledge and awareness are increased. This was done by training on the disease, its complications, ways of prevention, ways of transferring and consuming drugs, and follow-up of tests and treatment. The second step is the problem-solving phase, which was done to increase self-esteem and self-control. In this phase, after increasing parents' knowledge and attitudes about the disease, they would be included in care programs. The third step is educational participation. The fourth step is evaluation, which was performed in two stages, i.e., at the end of the intervention and one month later.

Parents were first asked to complete a questionnaire on the burden of parental care. Then, four 40-minute sessions were performed for four consecutive weeks (one session per week). Before each session, the meeting time was set and the sessions were held in the ward study class for the convenience of parents. Empowerment sessions were performed as follows:

In the first session (40 minutes), the researcher used face-to-face training with parents about childhood cancer, common signs and symptoms, diagnostic techniques, and treatment programs, considering the stage and condition of their child's illness; Then, these parents were given basic training in this field. It should be noted that this meeting was presented separately to all parents in the intervention group.

To implement the second phase of the empowerment model, the second session was performed in groups of 6 to 3 people for 40 minutes, and the parents were asked to discuss ways to communicate and exchange views with the hospital treatment team. In this session, they shared their experiences and information about the treatment and evaluation and control of therapeutic side effects. Other topics discussed in this session included ways to prevent infection, control and relieve pain, side effects of medications, improve self-control in the face of children with cancer and their problems, as well as ways to support other family members. During this session, the researcher tried to direct the discussion indirectly and lead the group towards enriching self-efficacy.

During the third session, in order to implement the third phase of the empowerment model, each participant was asked to teach one of their family members, who is responsible for child care, about what they had learned in the previous two sessions, and answer the researcher's questions under his or her indirect supervision. During this session, any potential problems, such as forgetfulness or the transmission of incorrect information by trained parents, were immediately corrected by the researcher.

In the fourth or the final evaluation session, the researcher evaluated all the participants in the intervention group by asking questions about the whole taught content and the items that were discussed in the second and third sessions, and lastly, addressed all the remaining ambiguities.

It is important to note that the topic of the previous session was evaluated by the researcher at the beginning of each session with one or two questions. Exclusion criteria among the parents of the intervention group included reluctance to continue participating in the study and non-attendance at training sessions. Even if one family member was absent in the third training session, it led to the exclusion of the whole family from the study. It is important to note that cases of the control group received all routine hospital care within a month. After the intervention and one month later, self-efficacy and hope questionnaires were completed by the subjects of the intervention and control groups. It should be noted that all participants in this project were under psychological control and evaluation. Also,

the meetings were conducted separately from the ward routine therapy and none of the costs of conducting research interventions were borne by those present in the study.

Analysis 1)

Variable Group		Control group N (%)	Intervention group N (%)	
Level of education	Secondary education	7(25.92)	12(44.44)	X ² =0.239 P=0.760
	Undergraduate	8(29.62)	10(37.03)	
	Postgraduate	12(44.44)	5(18.53)	
Marital status	Married	26(96.29)	27(100)	X ² =1.008 P=0.907
	Divorced	1(3.70)	0	
Number of childre	1	8(29.62)	8(29.62)	equal
	2	12(44.44)	12(44.44)	
	3	7(25.92)	7(25.92)	
Occupation	Self-employed	2(7.40)	1(3.70)	X ² =0.899 P=0.149
	Housewife	10(37.03)	11(40.74)	
	Employed	15(55.56)	15(55.56)	
	Retired	0	0	
Age	15-25	12(44.44)	12(44.44)	equal
	26-35	10(37.03)	10(37.03)	
	36<=	5(18.53)	5(18.53)	
gender	Male	15(55.56)	14(51.85)	X ² =-0.40 P=0.100
	Female	12(44.44)	13(48.14)	
Economic status	Low	8(29.62)	8(29.62)	equal
	Moderate	12(44.44)	12(44.44)	
	Good	7(25.92)	7(25.92)	
Housing status	Owner	12(44.44)	12(44.44)	X ² =-0.567 P=0.987
	Rental	8(29.62)	10(37.03)	
	Mortgage	7(25.92)	5(18.53)	
	Other	0	0	
Place of residence	Tehran	23(85.18)	20(74.08)	X ² =-0.506 P=0.900
	Other cities	4(15.81)	7(25.92)	
History of underlying diseases	Yes	20(74.08)	20(74.08)	equal
	No	7(25.92)	7(25.92)	
Gender of child	Girl	20(74.08)	20(74.08)	equal
	Boy	7(25.92)	7(25.92)	

2)

Group Variable		Control group	Intervention group	Test	
Self-efficacy (Sherer's scale)	Self-efficacy before intervention	Moderate self-efficacy	0(0)	0(0)	T= 0.1 P= 0.096
		High self-efficacy	22(81.48)	5 (18.52)	
		Mode	4	1	
	Self-efficacy after intervention	Moderate self-efficacy	0(0)	0(0)	T= -4.322 P= <0.001
		High self-efficacy	7(25.93)	20(74.07)	
		Mode	5	1	
Hope (Snyder's scale)	Hope before intervention	Low level of hope	0(0)	0(0)	T= -0.0233 P=0.456
		Moderate level of hope	12(44.44)	2(7.40)	
		High level of hope	10(37.03)	3(11.11)	
		mode	5	3	
	Hope after intervention	Low level of hope	0(0)	0(0)	T=-4.756 P= <0.001
		Moderate level of hope	5(18.52)	0(0)	
		High level of hope	0(0)	22(81.48)	
		mode	4	1	

There was no significant difference between the intervention and control groups.

According to the above tables, it was found that the level of self-efficacy before the intervention was significantly lower than the level of self-efficacy after the intervention. In this test, the level of average self-efficacy was zero in the control group and zero in the intervention group. At high level of self-efficacy in the control group, this number reached 22 people (81.48%), and in the intervention group, it was 18.52%. No significant differences were found between the control and intervention groups in terms of the level of self-efficacy before the intervention. The probability value in these two groups was 0.096, which is very close to one. As a result, the null hypothesis is not rejected and hypothesis one is rejected based on the difference between the two groups in terms of the average of the two dependent societies.

After the intervention, none of the cases of the two groups had a moderate level of self-efficacy. However, at high level of self-efficacy, 7 people in the control group and 20 people in the intervention group had high levels of anxiety. In these conditions, by comparing the mean of the two dependent communities (paired t-test), it was observed that there was a significant difference between the two groups, and the null hypothesis is strongly rejected. None of the cases in the intervention and control groups were at a low level of hope (based on Snyder's scale) before the intervention. Also, 44.44% of the subjects in the control group and 7.40% of the subjects in the intervention group were in a moderate level of hope. But 10 people (37.03%) in the intervention group had a high level of hope. According to the test statistics, these two groups were not significantly different from each other and the null hypothesis is confirmed.

None of the cases in the intervention and control groups were at a low level of hope (based on Snyder's scale) after the intervention. Also, 18.52% of the subjects in the control group and none of the subjects of the intervention group were in a moderate level of hope. But 22 people (81.48%) in the intervention group had a high level of hope. Although the difference in the number of cases can be understood, for the overall result and the correctness of the hypothesis, paired t-test (average of two dependent groups) was used. According to the test statistics, these two groups were significantly different from each other and the null hypothesis is not confirmed.

Results

After the intervention, positive effects were observed on the self-efficacy scale (Sherer's scale), and the levels of hope (Snyder's scale) in the intervention group were higher compared to the control group. Also, a great number of cases in the intervention group were at a high level of hope. Whereas low levels of hope were not observed in the

control and intervention groups, and moderate levels of hope were more frequent in the control group than the intervention group. On the other hand, after the intervention, the number of cases with high hope was increased in the intervention group, and this increase was not found in the control group. The same was true for the self-efficacy scale, and after the intervention, the subjects of the intervention group showed positive conditions with high efficacy.

3)

Variable	Group effect	Time effect	Carry over effect
Self-efficacy	0.001	0.003	0.001
Hope	0.003	0.002	0.001

Discussion

The present research was a quasi-experimental study that was conducted to determine the effect of family-centered care on self-efficacy and hope in parents of children with cancer. According to the results obtained from the self-efficacy (Sherer General Self-Efficacy Scale) and hope (Snyder's Hope Scale) scales, the cases of the intervention group were improved in comparison with parents of the control group. High levels of hope were more frequently observed in the intervention group, while low levels of hope were not found in the control and intervention groups. Also, moderate levels of hope in were more frequently observed in the control group compared to the intervention group. The same was true for the self-efficacy scale, and in the intervention group, after the intervention, the cases showed positive conditions with high efficacy. The highest percentage of parents in the control and intervention groups were in the age range of 25-25 (44.44%). There was no significant difference between the two groups in terms of age. The highest percentage of parents in the control group (44.44%) were postgraduates, and the highest percentage of parents in the intervention group (44.44%) had secondary education. Despite this difference, training has been effective. Family-centered care can be an important step in improving the mental status of parents of children with cancer. Therefore, due to its low cost, safety, and effectiveness, family-centered care is recommended to be used in oncology departments (34, 35).

Shoghi et al. studied the effect of the family-centered empowerment model on parents of children with cancer, and it was shown that the empowerment of parents of children with cancer has an effect on reducing the burden of care and the use of this empowerment model is recommended to the treatment team, especially nurses. (36) In the present study, 54 parents participated, which is less than the number of samples in the study by Shoghi et al., but the results of the two studies were similar. Also, it has been observed that family-oriented services were indirectly related to the quality of life and life satisfaction through the burden of care (11). A clinical trial study was performed on 86 mothers of children with cancer with the aim of evaluating the effect of an educational intervention based on self-efficacy theory on maternal care behavior. The results showed that educational intervention improved maternal care behavior with increasing self-efficacy. In the present study, most of the participants were fathers, but the results were in line with the results of the above study. Another trial was conducted by Etemadifar, by performing educational sessions for parents five times per week. In their study, 61.3% of cases were female and were 38.7% male caregivers with a mean age of 37.5 years. Questionnaires were completed in three stages before, immediately after, and two months after the intervention. The results showed that the family-centered intervention program reduced the stress, anxiety, and depression of caregivers due to the feasibility, simplicity, and usefulness of the intervention (38), which was in line with the results of the present study. The family-centered empowerment model helps patients and their families identify their flaws and shortcomings and have enough power to change their current situation. This sense of ability is gained through information, support, and skills that improve the patient's condition. As the results showed, the implementation of the family-centered empowerment model was effective in improving the lifestyle of school-age children with leukemia. It is also recommended for other patients with leukemia (39).(40)(41)42)

Conclusion

In this study, it was demonstrated that family-centered care could be effective in improving self-efficacy and hope in parents of children with cancer. Family-centered care may also affect parental psychological functioning, regardless of the treatment status or age of their children. In general, according to our findings, it is recommended that family-centered care be provided in pediatric oncology wards.

Hamidreza khoshnezhad Ebrahimi conceived and designed the evaluation and drafted the manuscript. Shabahangjafarnejad participated in designing the evaluation, performed parts of the statistical analysis and helped to draft the manuscript. Neda ashayeri re-evaluated the clinical data, revised the manuscript and performed the statistical analysis and revised the manuscript. Baharak Ranjbaran collected the clinical data, interpreted them and

revised the manuscript. SoroorSohrabi and Somayeh Esmaelilian re-analyzed the clinical and statistical data and revised the manuscript. All authors read and approved the final manuscript.

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