Original Article

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Nursing Support System for Mothers of Hospitalized Leukemic Children: A Comparative Study

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Abstract

Background: In addition to child, families can be influenced traumatically by the leukemia and hospitalization. Adopting the philosophy of a family-centered care approach can maximize the well being of pediatric patients and their family. The philosophy is based on the collaboration of the family, nurses and hospital staff to plan, provide and evaluate care To establish the best plan of care for leukemic child and improve family stability as well, nurses should support the family. The current study was conducted to compare the opinions of mothers with nurses regarding the availability of nursing support for mothers of hospitalized leukemic children in a pediatric oncology ward.

Materials and Methods: This comparative descriptive study was conducted on all mothers with leukemic children who were hospitalized in a pediatric oncology ward (n=89) of Shahid Sadoughi Hospital, Yazd, Iran and all nurses (n=21) in this ward during 2015. Data were collected through the NPST(Nurse-parent Support Tool) and demographic questionnairs. The obtained data were analyzed with SPSS (version 22).

Results: The most important dimensions in terms of mothers' opinions were "emotional" (3.34±0.56) and "quality of care" (3.26 ±0.55) and considering nurses' opinions were "emotional" (3.22± 0.47) and "informational-communicational" (3.22± 0.43). Mann-Whitney test showed no significant differences between mothers' and nurses' opinions regarding four subscales of nursing support ($p < 0.21$).

Conclusion: The opinions of mothers and nurses in the pediatric oncology ward did not differ regarding the availability of nursing support. However with respect to the overall mean of nursing support from mother's perspective, it is necessary to provide further support for mothers by the nurses. The results of this study may be useful for improving nursing care in oncologic wards.

Key Words: Children, Family, Leukemia, Mothers, Nursing, Support

Introduction

Cancer is one of the major causes of child mortality in developing and developed countries (1).The disease is the second leading cause of death in children younger than 14 years, while 4% of deaths occur before the age of 5 years and 13% between the ages of 5 to 10 years old (2). Leukemia is the most common and acute malignancy in childhood. Acute lymphoblastic leukemia (ALL) is a malignancy of lymphocytes and accounts for approximately 75% of all leukemia. Acute myeloid leukemia (AML) arises from the myelocytic cell line and represents 20-25% of childhood leukemia (3, 4). In the recent years, treatment of leukemia in childhood has advanced rapidly. Treatment program for pediatric ALL consists of remission, consolidation, re induction, intensification, maintenance chemothropy, and central nervous system leukemia therapy (5). Generally, the first hospitalization period for the children lasts 2 to 3 months to achieve induced remission. During this period, the children must be in the hospital for 15 days depending on their treatment program (6, 7). Although advances in the treatment of cancers have been achieved and the survival rate of children with leukemia

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increase significantly (8), the crisis caused by the disease and hospitalization of children are one of the main sources of tension and anxiety among families. Disbelief, guilt, anger, and hopelessness are the emotions that parents experience. Moreover, they are expected to be involved in physical, emotional, and mental care of their children. Parents also need psycho-social support to achieve these objectives (9, 10). Although the needs of children are very important during hospitalization time, the needs of their mothers are also greatly important as care givers of their children (11). Because parents are required to provide adequate care and support to their children, they need to have peace of mind. For this purpose, support and understanding their feelings and concerns are essential to providing better and higher quality care (12, 13). It is conceptualized that nursing support of the parents of hospitalized children would help parents to maintain their role as a parent and to reduce stress (14). The mothers need nursing support to provide their needs. The nurses must maintain a close relationship with mothers to provide family-centered care and maintain the integrity of the family (15, 16, and 17). The role of nurses in support of children with chronic diseases such as leukemia cannot be ignored. To relieve physical and emotional problems in mothers and their children, nursing staff should help them. Maximum benefit of interventions of health care staff is realized when they can identify stressors and help mothers and children to cope with the disease. Therefore, the most appropriate time to deal with this problem is at the early stage and immediately after diagnosis. Without the support of nurses, the family is exposed to crisis and may family members use improper solutions to cope with their child's illness. Nevertheless, the nurses cannot have major role in the early stages; their role is very valuable in the later stages (18). In this regard, training adequately nursing staff to be able to help children and parents is noteworthy. They can support, give information, educate the parents, care, and help the children and their parents to adapt to the new situation caused by the disease (19). Giving information to parents must be consistent and compatible to the disease. Moreover, parents should find courage to ask questions to avoid misunderstanding (20). In fact, nurses are in a unique situation to interact with family members of patients (21). They can be used as a counselor in a proper situation in order to help the family and provide guidance and training to them (22). According to Goldenberg & Goldenberg (2012) , nursing studies emphasize the importance of family- centered care in order to provide a supportive environment for patients and their families (23). Nurses provide proper and important conditions for parents of hospitalized children individually or collectively. In fact, the environment provided by nurses is the main reality of life for parents. Nurses also give wide information to parents while interacting with them. The reactions of nurses are very important for adjustment of parents and children during illness and hospitalization. These subsequently affect family health after discharge from the hospital (24-27). Professional support of parents with afflicted children has been the subject of a number of research. For instance, Lee TY et.al aimed to determine the fathers' support as realized by mothers, Moke and Leung studied the nurses as the providers of support for mothers of infants (28, 29). Furthermore,the sample of Sanjari' et al., study was limited to parents in pediatric university hospitals and little generalization could be made across other clinical settings. Their study was also limited by the use of a sample of parents (30). These studies were mostly conducted with regards to parent's viewpoint and little attention was paid to the nurses' views. The promotion of the role of parents, especially mothers, is the main goal of nursing interventions. Assessment

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of nursing support of mothers can be useful in diagnosing problems and needs. There have been a number of studies which have explored the extent of nursing supports for mothers with hospitalized children. However, most of them have considered the viewpoints of the parents, disregarding the viewpoints of the care givers. The present study was done to answer the following question: Is there a difference between the opinions of the mothers and nurses regarding the availability of the support provided by nurses for mothers with hospitalized leukemic children in pediatric oncologic ward.

Materials and Methods

A comparative descriptive design was used to allow the examination of the opinions of mothers and nurses regarding the availability of the support provided by nurses for mothers with hospitalized leukemic children in a pediatric oncology ward. The study population consisted of all mothers (n=89) and all nurses (n=21) in the pediatric oncology ward at Shahid Sadoughi Hospital affiliated to Shahid Sadoughi University of Medical Sciences, Iran. This study was done by census method during the first 6 months of the year 2015.Mothers included in this study had leukemic children hospitalized for at least 7 days and had no problems in verbal communication and were willing to participate in the study. Only the nurses who worked at least 10 shifts in a month in the period of this study were included. After informing the mothers and nurses about the purpose of the study, the questionnaires were completed through individual interviews with mothers and nurses.

Instruments

A three part instrument was used in this study. The first part was consisted of some questions (i.e. mothers' and children's age, gender of children, education level, occupation, length of hospitalization). The second part was consisted of some questions about nurses (i.e. age, education, work experience, marital status, and type of shift work) .The Nurse Parent Support Tool (NPST) developed by Miles, Carlson, and Brunssen in 1998 was applied which consists of 21 items classified into four subscales: information and communication support (nine items) , emotional support (three items), esteem support (four items), and quality caregiving support (five items). The range of scores were from 1 ‘almost never’ to 5 ‘almost always’ (6) with higher scores showing a greater amount of support provided by the nursing staff. The maximum score for each subscale depends on the number of items .Content validity of the NPST was established by Miles in two earlier studies of parents of hospitalized children (27, 31) and through a literature review. The validity of the scale was determined by Akbarbegloo (32) et al., in 2009. Reliability of the scale was also determined by Cronbach's alpha (0.9 for mothers and 0.96 for nurses). Although the NPST was prepared for parents, researchers changed verbs in items for nurses and used items in the third person format for mothers and first person for nurses (33). For example, in mothers' sheet, it was “nurses allowed me to be involved in my child's care whenever possible” and in nurses’ sheet it was “I allow parents to be involved in their child's care whenever possible.

Data collection

Informing the mothers and nurses about the purpose of the study, the questionnaires were completed through individual interviews with mothers and nurses (6).

Ethical considerations

The Institutional Review Board and The Research Ethics Committee of Shahid Sadoughi University of Medical Sciences (Ethic code: ir.ssu.rec.1394.197) Yazd, Iran, approved the study. In addition, required permission was received from

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relevant authorities in Shahid Sadoughi Hospital and the pediatric oncology ward. All participants in the study were assured of the confidentiality of their personal information and absence of any constraint to participate in the study.

Statistical analysis

Data were analyzed using SPSS statistical software version 22. Descriptive statistics (frequency, mean, and standard deviation) were run. Moreover, the Mann- Whitney test was used to determine any significant differences in the groups of mothers and nurses regarding provided nursing support subscales. P. value less than 0.05 was considered to be significant.

Results

The analyses of the demographic information are presented in Tables I and II. Briefly, mothers' age ranged from 17 to 48 years (M = 30.73, SD = 7.32). Considering educational level, 41.6% of mothers had less than high school education, 31.5% had high school education, and 16.8% had university education, and 10.1% were illiterate. Moreover, 93.3% of mothers were ouseholder. The age range of nurses was from 23-45 years old (32.38, SD= 7.15). The nursing experiences in pediatric oncology ward in majority of them were 11-15 years (71.4%).(Table II). The average of nursing experience was 9.28± 7.58 years and mean of nursing experience in pediatric oncology ward was 5.42±4.23 years. Considering martial status, 85.7% of nurses were married. Finally, 85.7 % of nurses worked in rotating shifts.

Forty five patients were boys (50.6%) and fourty four patients were girls (49.4%).Their mean age was 4.73±2.54.The mean of hospitalization length was 6.85± 5.98 days in the oncology ward and its distribution was 7 to 90 days. Based on mothers' viewpoints, the overall average of nursing support for mothers was 3.39±0.54 and based on the nurses' viewpoints, it was 3.31±0.39. According to viewpoints of mothers, the most received support was related to "quality of care" and "emotional" subgroups and the most provided support based on the nurses' points of view was related to "emotional" and "information-communicational" subgroups. The Mann-Whitney test showed no significant difference between mothers' and nurses viewpoints within the four domains of nursing support provided for mothers in the pediatric oncology ward (Table III).

Table I. Mothers' Demographic information (n = 89)

variables		n	%
Age	**17-25**	23	25.9
	26-35	48	53.9
	36-45	12	13.5
	> 45	6	6.7
Educational level			
Illiterate		9	10.1
Less than high school		37	41.6
High school graduate		28	31.5
University graduate		15	16.8
Job			
Employee		6	6.7
householder		83	93.3
Total		89	100

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Table II. Nurses' Demographic information (n = 21)

variables		n	%
Age	**23-29**	9	42.9
	30-36	7	33.3
	37-45	5	23.8
Work experience in hospital	**1-10**	13	61.9
	11-20	5	23.8
	21-25	3	14.3
Work experience in pediatric oncology ward	**1-10**	6	28.6
	11-15	15	71.4
Total		21	100

Table III: Mean values of mothers (n=89) and nurses (n=21) regarding provided nursing support subscales and their comparison

Provided nursing support subscales		Mean (SD)	Mean Rank	Mann whitney U	P-Value
Emotional	**mothers**	3.34±0.56	57.19	784	0.24
	nurses	3.22±0.47	48.33		
Communication-Information	**mothers**	3.22±0.55	56.27	866	0.60
	nurses	3.22±0.43	52.24		
Esteem	**mothers**	3.14±0.69	57.05	796.5	0.28
	nurses	3.04±0.51	48.93		
Quality care-giving	**mothers**	3.26±0.55	56.83	816	0.35
	nurses	3.19±0.46	49.86		

SD: standard deviation

Discussion

The findings of this study demonstrated the nurses' perception of mothers' supportive needs for mothers with hospitalized leukemic children in pediatric oncology ward. The results showed that the total mean nursing support based on mothers' viewpoints was 3.39±0.54 and based on nurses' viewpoints was 3.31±0.39. Statistical analysis of the obtained data revealed a non-significant difference between mothers and nurses regarding support on all subscales. This result was expected due to the sample size of the nurses, which could not be avoided because of the few available nurses in pediatric oncology ward. The facilities in the pediatric oncology ward could be another factor that could affect inversely the mothers' and the nurses responses. Sanjari etal., evaluated 183 mothers' and 47 fathers views on nursing support and presented an overall average nursing support of 4.7±0.7 that was higher than our study (30). In this study, based on mothers'

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viewpoint, the most level of received support was related to "quality of care" and "emotional" subgroups and the lowest level was related to "esteem" domain. According to the results of Valizadeh et al., (2012), the highest level of support in parents of newborns in NICU was related to "quality of care" and "informational-communicational" subgroups and the lowest level was related to "emotional" and "esteem" domains. These results were consistent with our results in terms of "quality of care" priority and in contrast to our study regarding the status of "esteem" domain (33). Mok' and Leung study also showed that parents had received the communicative- informative support more than other scales. However, emotional support was at the lowest level (28). In a study by shields et al., parents believed that if they had received enough information, they were able to get a majority of their needs (9). One of the tasks of the nursing team is to increase the ability of patients and their parents to participate in their care. Having the right decision makes the children feel that they are important and gives the parents a sense of contributing to their heath care (34). Hopia et al., (2005) stated that nurses can promote family health during hospitalization through increasing the quality of care, reducing emotional stress, coping, and communicational support for families. Receiving support and effective communication from the nursing staff are very important for parents (35).

In fact, parents are expected to contribute to physical, emotional, and mental care of their children while they themselves need psychosocial support too (9). They also want to receive correct information from nurses about their present child's situation and changes to their children's status (10).

In Yui and Twinn's study, parents expressed their needs for understanding their reaction, recognizing the fear of hospitalization, support and information, allocating time to themselves, and acquiring earning skills (36). In a study by Kyritsi et al., (2005), Greek parents presented their needs as follows: receiving information about the prognosis and the child's condition, support, and honesty in the delivery of health care (12).

This study demonstrated that the most important domain based on the view point of mothers were "quality of care" and "emotional" domains. The lowest level of support was related to the "esteem" domain. Akbarbegloo et al., (2009) points out the most received supports as "instrumented care" and "communicative-informative" subgroups based on mothers' viewpoint; however, "esteem" domain had the lowest level of received support which is in line with our study. Therefore, it is necessary to plan for promoting family-centered care for parents in an intensive care unit (32). Bruce and Ritchie assessed perception of nurses about family centered care activities. They noticed that all of the items were important and necessary in family centered care. However, although nurses claim that they are well aware of their importance, they do not regard them in their routine (37).In general, important factors in the nurses' supportive role include response to the problems of the family, helping them to express their feelings, and balancing family members. Promotion of communicative behavior also increases the social skills of nurses and ultimately improves the quality of care (38).In this study, there was not a significant difference between mothers' and nurses viewpoints within the four domains of nursing supports provided for mothers in a pediatric oncology ward. These results indicated that mothers and the nurses generally have similar opinions and nurses expressed their viewpoints realistically.However, the nurses must develop their knowledge of nursing support. Manongi and co-workers (2009) concluded that if nurses' needs in their working environment are not met, it is unlikely that they will be able to shift focus on the needs of parents (39).

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Limitations

The sample of this study was limited to mothers in pediatric oncology ward of a university hospital. The second limitation concerns about difficulty of access to fathers of children participated in this study. Therefore, further studies with larger population, with father involvement are recommended. The facilities in the ward or hospital were another confounding factor that could inversely affect the mothers and the nurses' responses.

Conclusion

The results of this study confirmed the consistency in opinions of nurses and mothers toward the availability of the nursing supports provided for parents with hospitalized leukemic children in pediatric oncologic ward. However with respect to the overall mean support for mothers, providing better support for parents in pediatric oncologic wards through supporting the parents (especially mothers) is recommended. This study provides nurses some information in order to improve nursing care in oncologic wards.

Conflict of interest

There was no conflict of interest

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