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The relationship between unmet needs of parents with hospitalized children and the level of parental anxiety in Iran

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ABSTRACT

Purpose: This study aimed to investigate the relationship between parents' unmet needs with hospitalized children and the level of parental anxiety.
Design and methods: This correlational study was conducted on 194 parents with hospitalized children. The data were collected using the questionnaires of "revised needs of parents with hospitalized children" and "Zung's anxiety scale". The data were then analyzed through descriptive and inferential statistics using SPSS software version 19.
Results: There was a very weak positive relationship between the number of unmet needs of the sick child and the physical symptoms of anxiety ($P = 0.038$, $r = 0.149$) and overall anxiety score ($P = 0.018$, $r = 0.17$). However, there was no significant relationship between the number of unmet needs in other groups. Also, there was no significant relationship between the total number of unmet needs and parental anxiety. The most frequent unmet needs of parents, respectively, belonged to 1) support and guidance, 2) needs of other family members, and 3) comfort.
Conclusions: It might not be possible to obviate all the parental needs during the child's hospitalization. It is noteworthy that failure to meet those parental needs directly related to the child may cause anxiety for the parents.
Practice implications: Meeting the needs of parents regarding support and guidance, comfort, other family members, and needs directly related to the child is recommended to prioritize in pediatric nursing care.

Introduction

Every year, 70 to 90 out of every 1000 children experience hospitalization (Wilson & Rodgers, 2016, p. 1). The hospitalization of a child may result in psychological consequences such as anxiety and insecurity. Hospitalizations may also affect the child's family members and cause tension and anxiety among parents or the child's primary caregivers by creating new conditions and imbalances (Andrade, Alvarenga, Martimiano, Santos, & Nascimento, 2018; Çalbayram, Altundag, & Aydin, 2016). In addition to hospitalizing a sick child, issues such as medication, medical procedures, diet, comfort, and child safety can also cause parental anxiety (Çalbayram et al., 2016). These can create various needs in parents, including the need to receive information and support regarding their role in providing care for their hospitalized child. Moreover, parents may experience anxiety when their needs are not met (Afkar, Rasha, Khaled, & Marwa, 2019).

Studies on parents' needs indicate some parents do not have the ability or tendency to express their needs due to the feeling of helplessness and inadequacy in the hospital (Seyedamini, 2011). The nurses may have a different perception of the parents' needs despite paying attention to the cases. Therefore, the parents' needs are not efficiently met (Foster, Whitehead, Arabiat, & Frost, 2018). Failure to meet these needs or the nurse's inappropriate response to these needs might be an source of parental anxiety (Çalbayram et al., 2016).

Familiarity with the needs of parents is a part of the nurses' responsibility. Nurses can play an important role in identifying the causes of parental anxiety and reducing it by meeting children and their families' needs (Jones, Nowacki, Greene, Traul, & Goldfarb, 2017; Phiri, Kafulafula, & Chorwe-Sungani, 2019). Hence, it is necessary for the nurse, as a vital member of the health care team, to understand the needs of the parents (Aarthun, Øymar, & Akerjordet, 2018).

Family-centered care (FCC) as a philosophy for pediatric nursing involves providing responsive care. It meets the child's needs and priorities while also meeting the needs and priorities of the parents as the primary source of child support (Dall'Oglio et al., 2018; Feeg, Huang, Mannino, Miller, & Kuan, 2018). Protecting the family's integrity and controlling the everyday life situation during the provision of care for the hospitalized child might create several needs for the parents

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(Jones et al., 2017). Since parents do not have the required authority in the hospitals, this places them in more stressful situations (Andrade et al., 2018).

Paying attention to and understanding the needs of the parents involved in the child's care is as important as understanding the needs of the child; and can lead to the discovery of the child's needs and effective interventions (Feeg et al., 2018). Sometimes, the parents' needs reflect the child's needs (Karimi, Daneshvar, Sadat Hoseini, Mehran, & Shiri, 2008). If the needs related to the child's disease and hospitalization are met, parents can adapt to the new situation and provide the necessary support to their child (Bekmaz, Hojjati, & Akhoundzadeh, 2019).

Previous studies have proposed different classifications for parents' needs. Andrade et al. (2018), for example, have classified these needs into six groups of trust, reliability, information, support and guidance, physical and human resources, and the child and other family members (Andrade et al., 2018). Also, Afkar et al. (2019) classified these needs into four groups informational, psychosocial, physical-practical, and spiritual needs (Afkar et al., 2019). And finally, it is reported that some other researchers have classified these needs into seven groups: comfort, support and guidance, information, communication, mutual trust between the healthcare providers and parents, needs of the sick child, needs of other family members (Almasi, Cheraghi, Roshanaei, Khalili, & Dehghani, 2018; Karimi et al., 2008; Seyedamini, 2011).

Moreover, despite many years of promoting FCC in nursing, parents' needs are yet to be comprehensively met or understood (Khajeh, Dehghan Nayeri, Bahramnezhad, & Sadat Hoseini, 2017). Studies from different contexts revealed that the parent's needs for information, support and guidance not met appropriately (Afkar et al., 2019; Karimi et al., 2008; Lyu, Wong, You, & Zhou, 2019). This may be due to the difference between the perception of parents' needs by health professionals and parents' perception. Accordingly, some studies have compared parents and the health care providers' perceptions about the needs of parents. The results of these studies show that the two groups have different perceptions regarding some of the parents' needs, which, in turn, lead to neglecting some of the parents' needs (Foster et al., 2018; Karimi et al., 2008). Another study by Almasi et al. indicated that understanding parents' needs and providing proper support is essential (Almasi et al., 2018).

Mahmoud and Elkreem's qualitative study highlights the most important needs in three areas: support and guidance, information, and comfort (Mahmoud & Elkreem, 2017). Another seminal qualitative study was conducted on families' unmet needs with hospitalized children with cancer in China. The study stated that parents need an intimate and supportive view, sufficient information, and appropriate provision of basic needs (Lyu et al., 2019). Although few studies have been done in this area, those limited studies have shown that parents do have unmet needs. Failure to meet these needs may be a source of parental anxiety. This study aimed to investigate the unmet needs of parents with hospitalized children and parental anxiety levels.

Methods

Setting and participants

The participants of this cross-sectional and correlational study were 194 parents whose children were hospitalized in the Children's Medical Center Hospital affiliated to Tehran University of Medical Sciences. The sample size was determined considering the correlation coefficient of 0.23 (based on the pilot study) between unmet needs and anxiety and a confidence level of 0.95 and statistical power of 90%. The participants were selected using the convenience sampling method. The First Author (NZ) invited potentially eligible participants to be assessed for inclusion and exclusion criteria. Among parents invited to participate in the study, only a few parents declined our invitation; thus, the response rate was 98%. The inclusion criteria for the parents were: literacy and being the caregiver of a hospitalized child aged 2–12 years old in all inpatient wards except for the Intensive Care Unit (ICU) and Cardiac Care Unit (CCU); and the exclusion criteria were: being diagnosed with anxiety disorder, having a record of advanced-stage disease, the use of sedatives, anti-anxiety and narcotic medicine and experiencing stressful events in the past six months (e.g., the death of a close family member, divorce, or loss of job). The study protocol was reviewed and approved by the Ethics Committee of Tehran University of Medical Sciences. Moreover, the present study observed ethical considerations such as full coordination with the executives of the Children's Medical Center, ensuring the anonymity of the participants and the voluntary nature of participation in the study, and obtaining informed written consent from the parents.

Instruments

Three questionnaires were used to collect the data: the demographic information questionnaire, Zung's self-rating anxiety scale, and the revised “needs of parents of hospitalized children questionnaire”. All of the questionnaires were prepared in Persian and completed through interviews from January to April 2018. The collected data were then checked for completeness and cleaning.

Zung's self-rating anxiety scale (SAS) was used to measure anxiety. This scale has 20 items based on the physical-emotional symptoms of anxiety (including five emotional symptoms and 15 physical symptoms). The respondent was asked to respond to the questions based on his/her past week activities. The responses are in the form of 4 choices, including “never or rarely”, “sometimes”, “most often”, and “permanently or almost always”. The scores range from 1 to 4 in positive symptoms and from 4 to 1 in negative symptoms (items 5–9–13-19); therefore, the maximum score would be 80. Any score between 20 and 44 indicates normal anxiety, between 45 and 59 shows mild to moderate anxiety, between 60 and 74 shows significant to severe anxiety, and 75 or beyond indicates very severe anxiety (Zung, 1971). The SAS is a widely-used self-report anxiety scale, and its validity and reliability were assessed in several studies (Pang, Tu, & Cai, 2019; Setyowati, Chung, & Yusuf, 2019). The reliability of the Persian version of SAS was reported 0.84 based on Cronbach's alpha coefficient (Asgharzadeh & Jahanbakhsh, 2013).

Development a questionnaire for the needs of parents with hospitalized children

The “needs of parents with hospitalized children Questionnaire” (NPQ) was proposed in 1999 for parents with children aged 2 to 12 (Bragadóttir, 1999). Karimi et al. adapted and used this questionnaire in the Iranian context (Karimi et al., 2008). In this study, we used the inductive and deductive approaches to develop the “revised needs of parents with hospitalized children questionnaire” (RNPQ) by reviewing the related literature and using the items included in these two before mentioned questionnaires. The RNPQ consisted of forty-one items, some of which were generated from the interviews with parents about their needs. The face and content validity of the RNPQ were evaluated by a qualitative approach with a panel of experts (10 faculty members). The questionnaire's reliability was approved based on the Cronbach α coefficient of 0.88 in the pilot study on 30 parents from the same setting.

Similar to previous studies in the Iranian context (Almasi et al., 2018; Karimi et al., 2008; Seyedamini, 2011), the RNPQ assesses the satisfaction of parents' needs in 7 groups including 1) comfort (6 items); 2) support and guidance (12 items); 3) information (7 items); 4) communication (3 items); 5) mutual trust between the healthcare providers and parents (5 items); 6) needs of the sick child (4 items); and 7) needs of other family members (4 items). The responses range on a scale of 0 to 2: not at all (0), to some extent (1) and fully (2) where “not at all” indicates the unmet needs of parents.

Statistical analyses

The data were analyzed using descriptive statistics, Spearman correlation coefficient, and Mann-Whitney and Kruskal-Wallis tests through SPSS software v.19. Regarding the distribution of the data, the parents' age was the only quantitative variables with normal distribution, and all the other variables had a non-normal distribution. Given that non-normal distribution of anxiety (SAS) and its two subscales (Emotional Symptoms and Physical Symptoms) as well as the seven groups of unmet needs, the Spearman test was used to investigate the correlation between the number of unmet needs and parental anxiety. Moreover, the Mann-Whitney and Kruskal-Wallis tests were used to analyze the relationship between other demographic information and the two main variables (parents' unmet needs and parents' anxiety). The level of significance of <0.05 was considered for in all the tests.

Results

The age of the parents' participating in the study ranged from 17 to 48 years, with a mean and standard deviation of 32.16 ± 6.24. The median, the first and the third quartile of the hospitalized child age were 3 (2,7) years, the duration of the disease was 120(14,730) days, and the length of hospitalization was 4(2,8) days, respectively. The majority (95.9%) of the parents were mothers. Most of them had health insurance (94.3%). More than half of the families were living in urban areas (58.8%). The result also showed that 53% of the children suffered from chronic diseases, and the rest were hospitalized with acute illness. Besides, more than half of them (59.8%) had a history of hospitalization. Most parents (79.4%) did not experience hospitalization for another child. The details of the demographic information are presented in Table 1.

Parents reported having as many as 0 to 32 unmet needs with a median and interquartile range (IQR) of 6 (8). Out of the total number of 194 parents, only 5.7% (11 parents) had all their needs met, and 94.3% of the parents reported at least one unmet need. Table 2 shows, the most frequent unmet needs of the parents were related to the needs of support and guidance (group 2), needs of other family members (group 7), and comfort (group 1), respectively. Three items in group 2 were unmet in more than 50% of the cases. These items include: "I received information about the child's discharge since admission", "I was assured that if necessary, I can contact the ward even after my child's discharge", and "the parents whose children had the similar diagnosis were introduced to each other to discuss and transfer the experiences".

Table 1
Demographic characteristics.

Demographic Characteristics			n (%)
Child sex		Girl	85 (43.8%)
		Boy	109 (56.2%)
The number of children in family		One	72 (37.1%)
		Two	83 (42.8%)
		≥ Three	39 (20.1%)
Parents' level of education		Illiterate	2 (1%)
		< Diploma	67 (34.5%)
		Diploma	80 (41.2%)
		Associate	11 (5.7%)
		Bachelor	29 (14.9%)
		Postgraduate	5 (2.6%)
Parents' employment status	Father	Unemployed	16 (8.2%)
		Employed	178 (91.8%)
	Mother	Housewife	181 (93.3%)
		Employed	13 (6.7%)
Golden Baby		Yes	50 (25.8%)
(A child who is the result of infertility treatments)		No	144 (74.2%)
Health insurance coverage		Yes	183 (94.3%)
		No	11 (5.7%)

According to Zung's anxiety scale, more than half of the parents (66.5%) had normal anxiety levels, and 31.4% had mild to moderate anxiety. Only 2.1% of the parents had significant to severe anxiety, and no parent had the most severe anxiety.

The results showed that there was a very weak positive relationship between the number of unmet needs related to the sick child and the physical symptoms of anxiety ($r = 0.149, P = 0.038$) and the total anxiety score (SAS) ($r = 0.17, P = 0.018$). There was no significant relationship between the number of unmet needs in other groups of needs and the total number of unmet needs with parental anxiety.

The Spearman test did not show a significant relationship between the hospitalized child age, parents' age, the duration of disease, the duration of hospitalization, and the parents' total anxiety score and the total number of unmet needs (Table 3). The Mann-Whitney and Kruskal-Wallis tests results did not indicate any significant relationship between qualitative demographic characteristics and the total score of parents' anxiety and the total number of parents' unmet needs.

Discussion

The hypothesis of this study was that an increase in the number of unmet parents' needs was associated with an increase in parental anxiety. It was based on the statements of Khalilzadeh et al. and Andrade et al. that meeting and paying attention to the needs of parents can lead to the reduction of parental anxiety (Andrade et al., 2018; Khalilzadeh, Khorsandi, Feizi, & KHalkhali, 2013). The results showed no association between the number of parents' unmet needs except the needs related to the child and parental anxiety. Consequently, this finding does not support the study hypothesis. It is consistent with the prospective cohort study, which examined the relationships between perceived need fulfillment for parents, parents' participation in hospital care, and parents' psychological distress during a child's hospitalization. In the mentioned study, Jones et al. used the Hospital Anxiety and Depression Scale for measuring psychological distress with two subscales of depression and anxiety. The result indicated no correlation between anxiety and perceived need fulfillment, but it showed that the more the parents' needs are met, the less their psychological distress (Jones et al., 2017). We found only a weak association with the needs related to the child and parental anxiety. It can be explained by Foster et al. that parents pay less attention to their own needs and focus more on the needs of their sick child (Foster, Young, Mitchell, Van, & Curtis, 2017). However, there is little empirical evidence about the relationship between them, and therefore, it is necessary to conduct further studies in this regard.

Around 33.5% of the parents in this study have experienced different anxiety levels, which might have underlying reasons. Jones et al. used a different tool to measure anxiety; therefore, we cannot compare the two studies' findings in terms of anxiety. They justified the result that various reasons could lead to not seeing this relationship. One of these is because the tool was not suitable for measuring pre-existing anxiety.

Given the impact of the hospitalization of a child on the parents, especially the mothers who usually stay in the child's bedside and spend the most time with him/her, anyone can feel the need for support, guidance, attention, and care (Lima et al., 2019). Insufficient attention to these needs causes parents to lose motivation to participate in child care (Khajeh et al., 2017). This may result from the nurses' busy schedule, which prevents them from paying enough attention to such needs, even though these needs are essential in the FCC context. The nurses should then pay attention to the parents/family's needs as long as they try to care for the child.

In this study, the second most frequent unmet parental need was "the needs of the other family members". In another study aiming to assess mothers' concerns and needs with hospitalized children and the level of nursing support with the NPQ questionnaire, "the needs of the other family members" was reported as the most frequent unmet need (Seyedamini, 2011). Meanwhile, Karimi et al. 's study about the

Table 2
The number of parents' unmet needs.

The number of unmet needs	Groups of Parents Needs						
	Group 1 Comfort	Group 2 Support and Guidance	Group 3 Information	Group 4 Communication	Group 5 Mutual trust	Group 6 Needs related to the sick child	Group 7 Needs related to other family members
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
0	80 (41.2%)	26 (13.4%)	108 (55.7%)	168 (86.6%)	138 (71.1%)	131 (67.5%)	70 (36.1%)
1–3	106 (54.7%)	87 (44.9%)	74 (38.2%)	26 (13.4%)	55 (28.4%)	62 (32%)	115 (59.3%)
>3	8 (4.1%)	81 (41.7%)	12 (6.1%)	0	1 (0.5%)	1 (0.5%)	9 (4.6%)

needs of parents with hospitalized children using the NPQ questionnaire showed that this category of needs (the needs of the other family members) was fully met (Karimi et al., 2008). This is one of the most important needs that nurses may ignore due to conditions, including crowded wards, limited visiting times, and the staff's busy schedule. Another limitation is the non-written regulation that requires the mothers to be at the patients' bedside as the companions. Fathers can only be with their children during visits; however, it is usually short that it cannot meet their needs adequately. In another seminal study, Calbayram and Aydin stated that restrictions over being at the child's bedside would cause or add to the fathers' anxiety (Çalbayram et al., 2016). Since allowing the fathers to participate in childcare can help them meet such needs (Khajeh et al., 2017), eliminating all the obstacles hinder the presence of a father at a child's bedside is necessary to improve FCC.

The present study results showed that “comfort” was the third most frequent unmet needs of parents. Karimi et al. also reported that this was the most frequent unmet need (Karimi et al., 2008). Besides, Mahmoud and Elkreem claimed that the needs for “support and guidance” and “comfort” were among the most critical needs for mothers (Mahmoud & Elkreem, 2017).

A qualitative study conducted in China also identified some parental needs, including the need for a comfortable environment (appropriate hygiene and adequate facilities) and the need for catering support services, which is the same as the need for “comfort” in the present study (Lyu et al., 2019). In 2017, another study was conducted on the basic needs of 109 parents with hospitalized children in the pediatric ward. The results showed that extra noises, lights, and staff activities during the night had caused sleep deprivation and parents' negative temper. This, in turn, has reduced the parents' ability to maintain focus and care for their sick child (Angelhoff, 2017). In recent years, despite the availability of amenities such as individual rooms for the mother and the child, welfare amenities for parents' relaxation, and entertainment facilities, the need for parental comfort is still not fully met. This might be due to the multi-occupancy room, the interference of staff's work with parental rest, and the loud noise in the ward. However, further investigation is required to identify other reasons.

Table 3
Relationship between demographic characteristics and parental total anxiety score and total number of unmet needs (The Spearman Test).

Demographic characteristics	Total Anxiety score		Total number of unmet needs	
	r	P-value	r	*P*-value
Hospitalized child age (year)	0.074	0.308	−0.13	0.071
Parents' age (year)	0.004	0.951	−0.102	0.157
Duration of the disease (day)	0.06	0.410	−0.072	0.315
Duration of hospitalization (day)	0.128	0.076	−0.037	0.612

Although paying attention to parental needs is a part of the FCC, various studies support FCC's effectiveness on improved health and quality of child and family care and reduced stress and anxiety (Christian, 2018); in the Iranian context, the meaning of the FCC is not clear for most healthcare providers. They believe it is related to family education (Khajeh et al., 2017). This could explain the results of the study. Therefore, more work should be done on this issue, and more studies are needed.

Practical implication

Based on this study's findings, nurses should pay more attention to parental support and guidance, parental comfort, and other family members' needs. Consideration of a child's needs may help decrease parents' anxiety. Furthermore, hospital managers should be more responsive regarding parents' unmet needs and should also create more satisfactory conditions to ensure the parents' comfort. The present study may pose the question of “what conditions have the parents with multiple unmet needs experienced” to be considered in future studies. It is also suggested to measure the relationship between parents' unmet needs with hospitalized children and their level of satisfaction in future studies.

Research limitations

The following limitations were observed in the present study:

1) Only eight fathers collaborated to complete the questionnaire. In the Iranian context, fathers have fewer opportunities to be at the bedside of their hospitalized child; therefore, the generalizability of the findings to the fathers is limited.
2) Despite ensuring confidentiality, the parents may believe that the nurses will become upset if they know about their unmet needs. This can affect the parents' responses, and they will tend to be more conservative in responding to the interview questions.

Conclusion

Parents' anxiety had a weak positive relationship with unmet needs related to the sick child. Paying attention to this issue may help nurses provide better care based on FCC; however, further study is needed.

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Declaration of Competing Interest

There is no conflict of interest.

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