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THE PRACTICES OF FAMILY-CENTERED CARE FOR HOSPITALIZED CHILDREN: COMPARISON OF IRANIAN MOTHERS AND NURSES' PERCEPTIONS

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ABSTRACT — BACKGROUND: Family-centred care (FCC) practices are challenging from the perspectives of both parents and health professionals.
PURPOSE: This study aimed to compare experiences with FCC practices between Iranian mothers and nurses.
DESIGN AND METHODS: This comparative cross-sectional study was conducted in 2019 on 233 mothers with hospitalized infants or children and 233 nurses working in neonatal intensive care units or pediatric wards selected using convenience sampling at five hospitals in Iran. Data regarding experiences about FCC practices among mothers and nurses was collected through the Perceptions of Family-Centered Care-Parent (PFCC-P) and the Perceptions of Family-Centered Care-Staff (PFCC-S) questionnaires containing the three subscales of Respect, Collaboration, and Support and 21 similar items. Descriptive and inferential statistics were utilized for data analysis using the IBM SPSS Statistics software. The significance level was set as $p<0.05$.
RESULTS: The mean and standard deviation of mothers' and nurses' experiences of FCC were 2.68±0.53 and 3.05±0.39; respectively (range, 1–4). The lowest score belonged to the subscale "respect." There was a statistically significant difference between mothers and nurses in their experiences with FCC practices in all three subscales. The nurses reported more positive experiences with FCC practices than the mothers did ($p<0.001$).
CONCLUSION: The mothers and nurses exercised FCC differently and nurses' experiences were more positive. Reasons behind the difference in mothers' and nurses' experiences with FCC practices should be investigated. Interventions are required to remove barriers associated with FCC practices in accordance with healthcare in Iran.

KEYWORDS — family-centered care (FCC), child, hospital, mother, nurse.

INTRODUCTION

Family-centered care (FCC) is a key philosophy in pediatric nursing [1]. Accordingly, the patient and family are at the center of all healthcare decisions and their values, perspectives and choices of patients and their families should be respected [2]. FCC is considered a holistic care model, but its application in health care has been defined using various methods [3]. Nursing literature has confirmed the central role of FCC in the improvement of outcomes for both children and families compared to the traditional medical model. FCC may associate with improving health and well-being, greater efficiency, better communication, parents' empowerment in caring behaviors, parent satisfaction with services, better care experiences, greater perceived safety, reduced unmet healthcare needs, and reduced inpatient medical expenditures [4].

Parental understandings of healthcare service may also be associated with belief in the practice of FCC, cultural beliefs, provision of support for community members, support for family members, family roles, and complexity of the child's health conditions [5]. Family members may not feel ready to take full care of their child and refuse to participate in care interventions [6]. Another reason for diversities in the practices of FCC is that it is more associated with families and children outcomes rather than nurses' perspectives.

The mothers' and nurses' perceptions of the practices of FCC have been studied in various design and settings using different instruments. Smith and Kendal (2018) conducted a qualitative study on collaboration in the management of childhood long-term conditions from the perspective of parents and health professionals [7]. Both of them valued collaborative practices, but differed in their expectations of collaboration and adopted different mechanisms to foster it. In a study to explore how parents of preschoolers with cerebral palsy experienced the level of family-centered services, Myrhaug, Jahnsen, Østensjø (2014) used the Measure of Processes of Care (MPOC) within primary health care in Norway [8]. Some results showed that among the five scales of MPOC including enabling and partnership, respectful and supportive, coordinated and comprehensive care, providing specific information, and providing general information, the both scales of respectful and supportive care, and coordinated and comprehensive care received the highest ratings.

While FCC is a concept well accepted in westernized countries, it is less so in developing countries cultures play major roles in determining how care is given by health professionals and perceived by parents [9]. Further research on FCC within western and non-western pediatric care areas are needed to build knowledge and practice [10]. In addition, the difference between the perceptions of families and health professionals about FCC can hinder its proper practices [11]. Therefore, this study was conducted to compare the mothers' and nurses' perceptions of the practices of FCC in a country located in the Middle East region, Iran. The study's hypothesis was as follows:

There is a significant difference between the mean scores of mothers' and nurses' perceptions of the practices of FCC.

METHODS

Participants and samplings

This comparative cross-sectional study was conducted in 2019 on mothers with hospitalized infants and children and nurses working in NICU and pediatric wards of 5 hospitals in an urban area of Iran. Four hospitals included just one or both the NICU and pediatric ward. One hospital was a large referral children's specialized hospital with a wide range of neonatal and pediatric diseases services including NICU, PICU, medical and infectious, neurosurgery, oncology and nephrology. Sampling was performed using a convenience sampling method. Each mother and nurse who was eligible and tended to participate, was selected and enrolled in the study.

Given alpha 0.05, beta 0.05, and the effect size of 0.30, the sample size was 233 nurses and 233 mothers. Inclusion criteria for the mothers were: ability to read and write, hospitalization of the child for more than 2 days, and physical and mental health based on their own reports because of mothers' perceptions. Inclusion criteria for the nurses were: the education level of higher than bachelor's degree, having at least one year of work experience in pediatric wards, and physical and mental health based on their own reports because of nurses' perceptions. It should be noted that in Iranian hospitals, because of the implementation of the Islamic principles and consideration of privacy matters, only mothers are allowed to stay with their children and only female nurses are employed for pediatric care.

Instruments

Two questionnaires were used to collect data on the demographic characteristics of the mothers and nurses. The demographic questionnaire for the mothers included 10 questions about age, the education level, number of children, residence place, duration of travel from home to hospital, difficulty of mother's presence in the hospital, presence of someone who cares for the child at home, age of the child at admission. The nurses' demographic questionnaire included 10 questions about age, marital status, number of children, education level, employment status, job title, experience, work shift, and work place.

To measure the mothers' perceptions of the practices of FCC, the Perception of Family-Centered Care-Parent (PFCC-P) and to measure the nurses' perspectives of the practices of the FCC, the Perception of Family-Centered Care-Staff (PFCC-S) were used. The questionnaires were designed by Shield and Tunner (2004) to compare the perceptions of the mothers and healthcare workers regarding the practices of FCC with the same number of items (20 items) [12]. The translation, cross-cultural adaptation, and psychometric testing of the both questionnaires in Persian language had already been conducted and published in an article in 2018. One item was added to each questionnaire and the number of items increased to 21 items after the designer's permission [13]. Items 1–6 were for the domain of respect, items 7–16 were for the domain of collaboration, and items 17–21 were for the domain of support. The four-point Likert scale was used from never (score 1) to always (score 4) and the mean score varied from 1 to 4. Based on judgment, the mean score of 1 to 2 was considered as a poor level of practices of FCC, 2.1 to 3 as an adequate level, and 3.1 to 4 as a good level.

Two items for support domain in PFCC are: "When I come to the hospital I feel welcome" and "I am able to be with my child during procedures". The same items for this domain in SFCC are: "When parents come to the hospital they are made to feel welcome", and "Parents are able to be with their child during procedures".

Two items for collaboration domain in PFCC are: "When decisions are being made about my child's care the staff includes me", and "I understand the written material that has been given to me". The same items for this domain in SFCC are: "When decisions are being made about their child's care, parents are included", and "Parents can understand the written material that has been given to them".

For the third domain, support, two item examples in PFCC are: "The staff listens to my concerns" and "The staff understands what my family and I are going through". The same items in SFCC are as follows: "Staff listens to parents' concerns" and "Staff understands what the parent and their family are going through".

For test-retest reliability, the questionnaires were given to 20 mothers and 20 nurses who were not in-

cluded as the study participants, twice within 2 weeks. The intraclass correlation of the PFCC-S and PFCC-P questionnaires were 0.88 and 0.80, respectively. The Cronbach's alpha coefficient as an internal consistency for both questionnaires was obtained at 0.85.

Data collection and analysis

The author of this study as a woman allowed entry into the field and visited the pediatric wards. She referred to five hospitals affiliated to Shahid Beheshti University of Medical Sciences at different times and days of the week and asked the eligible participants to fill out the questionnaires. Since the main research site was the children's specialist hospital with different pediatric departments, about 60% of the participants of each group (mothers and nurses) recruited from that site.

Sampling was performed in a manner that the equal number of mothers and nurses entered the study through independent sampling means that the nurses were not necessarily working with the children of the mothers in the study. Data was analyzed using descriptive and inferential statistics via the SPSS software version 18. The normality of data was assessed using the Kolmogorov-Smirnov test. The significance level was set as $p< 0.05$.

Ethical considerations

This study was carried out after the approval by the Ethics Committee of Shahid Beheshti University of Medical Science. Permissions were obtained from the hospitals' authorities prior to the study. Before data collection, the purpose and methods for the study were explained. The informed consent form was signed by the participants. The questionnaires were completed anonymously.

RESULTS

The mean and standard deviation was 30 ± 2.8. Also, 69.1% of them had an education level of high school or university. They mostly (46.6%) had one child and 43.78% had two children. Also, 92.27% of the mothers lived in the urban area and 46.78% of the mothers experienced moderate to severe difficulty to attend the hospital.

The mean and standard deviation of the nurses' age was 32.5 ± 4.2. Most of nurses (91.42%) had a bachelor education degree in nursing and the rest had master degree. 81.54% had a work experience of less than 10 years.

The mean score of the mothers' and nurses' perceptions about the practices of FCC was 2.68 ± 0.53 and 3.05 ± 0.39 respectively. In all domains and the entire FCC, the nurses obtain higher scores.

The Kolmogorov-Smirnov test confirmed normality of the data. The mean and standard deviation of the mothers' and nurses' perceptions about the practices of FCC was shown. We found a significant difference between the mothers' and nurses' perceptions about the practices of FCC. There was a significant difference between the perceptions of the groups in the respect domain ($p< 0.001$). The mean score of the nurses' score for this domain was higher than mothers (2.64 ± 0.50 and 2.41 ± 0.49, respectively). A similar result was reported for the second domain as collaboration, and a significant difference was reported between the perceptions of the mothers and nurses ($p < 0.001$). The mean and standard deviation of the mothers' perceptions of collaboration was 2.83 ± 0.66, for the nurses it was 3.28 ± 0.46.

The independent t-test showed a statistically significant difference between the mothers' and nurses' perceptions about support ($p < 0.001$), indicating that the mean scores of nurses were more than the mean scores of mothers ($3.10 \pm 0.51$and 2.52 ± 0.69, respectively). There was a statistically significant difference between the mean score of the mothers' and nurses' perceptions of the practices of FCC ($p < 0.001$) as the mean score of the nurses (3.05 ± 0.39) was higher than mothers (2.68 ± 0.53). Accordingly, the hypothesis of the study was confirmed as the mothers' and the nurses' perceptions of the practices of FCC in all domains had differences.

DISCUSSION

The aim of this study was to compare mothers' and nurses' perceptions of the practices of FCC in an urban area of Iran. Accordingly, the nurses' perceptions of the practices of FCC in the domains of respect, collaboration, and support were different from those of the mothers and the nurses reported higher scores. Contrary, Gill et al. (2014) stated that parents had a more positive perception of the practices of FCC compared to staff [14]. A qualitative study by Foster and Whitehead (2017) showed a difference in the perceptions of parents and health professionals regarding the practices of FCC [14]. In that study, the parents' perceptions were presented in terms of family, treatment, and communication and the health professionals' perceptions were family and treatment, indicating that parents emphasized more on communication. In a study on the implementation of FCC in care homes for children with neurodevelopmental disabilities, parents reported the weakness of FCC to respond to family needs, coordination, follow-up and support, and social resources [15]. Hill et al. (2018) found that parents identified unmet needs for the practices of the different aspects of FCC such as respect and dignity,

information exchange, and participation [16]. The findings of this study showed that the practices of FCC were not fully implemented from the perception of mothers and nurses. Similarly, in Saudi Arabia despite the confirmation of the importance of implementing FCC, nurses reported that this care model was not fully implemented in practice [17]. The health professionals in the Dall'Oglio et al. study (2018) reported that there was a significant gap between the perceptions of necessary and daily practices of FCC 9. Contrary, Gill et al. (2014) in a similar study in two large Australian hospitals reported that parents and staff reported satisfactory and good results of the practices of FCC. In another study in different European countries, all parents and nurses rated the practice of the FCC in the NICU high quality [14].

Reasons for not being complete practices of FCC could be a lack of education or awareness, fear of non-compliance with the family and its misconduct, lack of adequate knowledge of community resources for the fulfillment of family needs, beliefs and perceptions of employees of FCC and its potential benefits, lack of power of health professionals, low social support, lack of time, lack of resources, or insurance required for the implementation of FCC [18]. In addition to the above-mentioned barriers, communication issues, cultural barriers, and hospital policies could be other causes in the Iranian context. The mean scores of the mothers' and nurses' perceptions of the domain of respect were lower than the two other elements of collaboration and support. Conversely, Gill et al. (2014) reported a higher score for respect in parents and healthcare staff than other domains [14]. Respect means giving value to the cultural diversity of families and considering it a unique element. In the present study, the domain of respect consisted of parental greeting, the treatment of parents as parents and not typical visitors, respecting for the child and parent privacy, and the permission to stay with the child. Therefore, in comparison with other two domains, both mothers and nurses achieved a lower score on how the staff behaved with mothers and their children.

STRENGTHS OF THE STUDY

One of the strengths of this study was data collection using international questionnaires which had been already studied in term of psychometric properties in Persian language. The second strength point was to investigate the perceptions of mothers and nurses of the practices of FCC in a country in the Middle East which revealed the differences between the perceptions of the two groups about the practices of FCC.

LIMITATIONS OF THE STUDY

Given the fact that the study was carried out at a referral hospital in Iran, its results cannot be generalized to other pediatric wards in Iran. According to the authors, a limitation of this study was the effect of maternal fatigue and worries due to illness and child care and the nurses' fatigue due to workloads on the data collection. In addition, due to no presence of fathers in the pediatric wards, their perspectives were not assessed. The self-report identity of the data collection could affect the validity of the collected data. Therefore, observational studies on the practices of FCC are suggested.

Recommendations

Since the practices of FCC is not complete from the perspective of mothers and nurses, there is a need to improve the practices of FCC through modifying related policies in pediatric wards, provision of free visits for all family members, education and modification of nurses' beliefs about the importance of FCC and its dimensions, determining the role and extent of mothers' participation in FCC, education of nurses based on the continuous evaluation of family needs and aligning their understandings with those of mothers.

CONCLUSIONS

Considering FCC is a western healthcare model, it may not fit with all aspects of the health care culture in Asian and Middle Eastern countries. Therefore, more quantitative and qualitative studies on the implementation of this care model and its cultural adjustment are needed. Further studies on the factors associated with the low practices of FCC and differences in the perceptions of the mothers and nurses are required

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