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# The barriers to family-centered care in the pediatric rehabilitation ward: A qualitative study

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ABSTRACT

*Background:* Family-centered care (FCC) is one of the fundamental principles of care provision to children with disability (CWD). It is based on the collaboration of healthcare providers, patients, and families. However, there is limited information about the barriers to FCC in pediatric rehabilitation settings in Iran. This study aimed at exploring the barriers to FCC in the pediatric rehabilitation ward.

*Methods:* This descriptive qualitative study was conducted in 2022. Participants were nine rehabilitation staff and twelve mothers of hospitalized CWD purposively selected from the pediatric rehabilitation ward of hospital Rofeideh, Tehran, Iran. Rehabilitation staff were three nurses, a head nurse, a nursing manager, a medical specialist, a social worker, a physical therapist, and an occupational therapist. Eleven semi-structured interviews and three focus group discussions were conducted for data collection, and conventional content analysis proposed by Graneheim and Lundman (2004) was used for data analysis.

*Results:* The three main categories of the barriers to FCC in the pediatric rehabilitation ward were family-related barriers (subcategories: knowledge about child rehabilitation, sociocultural background, and participation), staff-related barriers (subcategories: knowledge, ethical concerns, and collaboration), and organizational barriers (subcategories: factors related to FCC policies, managerial factors, environmental factors, and factors related to the coronavirus disease 2019 pandemic).

*Conclusion:* The barriers to FCC in the pediatric rehabilitation ward are very diverse due to the long-term course of child disability and long-term interaction of families with rehabilitation centers. Data collection from both families and rehabilitation staff helped acquire an in-depth understanding about these barriers. More in-depth explorations of family-related barriers such as sociocultural factors are essential to determine the reasons for family resistance to healthcare providers' recommendations to develop more effective care plans.

## Introduction

Despite significant advances in medical and healthcare sciences, disability is still a prevalent problem among children (Hadders-Algra, 2022). According to the Convention on the Rights of Patients with Disability, children with disability (CWD) "include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis" (UNICEF, 2022). The report of the United Nations Children Fund showed that in September 2022, around 240 million children in the world, i.e., one tenth of all children, had some kind of disability (UNICEF, 2022). The Statistical Center of Iran also reported that in 2011, 82.5 children per 10,000 people had at least one disability, particularly cognitive and motor disabilities (Soltani et al., 2015).

Disability is a chronic problem and hence, CWD need lifetime rehabilitation services (Jeglinsky, 2012). Pediatric rehabilitation services include physical therapy, occupational therapy, speech therapy, swallowing therapy, balance therapy, respiratory therapy, neuropsychotherapy, vision therapy, use of assistive devices, and use of medications to reduce muscular spasticity and facilitate accurate body posture (Noetzel & Dosenbach, 2017). The ultimate goals of these services are to improve children's conditions and maximize their independence (WHO, 2023).

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As most pediatric disabilities are lifelong, their effective management needs a team approach with the active involvement of family members. Therefore, family-centered care (FCC) is considered the best approach to pediatric rehabilitation (Antunes & Vaz, 2021). According to the Institute for Patient- and Family-Centered Care, FCC is the effective and mutually beneficial partnership of healthcare providers, patients, and family members in planning, providing, and evaluating healthcare services (Johnson, 2012). In this approach, rehabilitation staff encourage CWD and their families to express their needs and thereby, improve their participation in making clinical decisions and implementing procedures (Houtrow, 2019). The principles of this approach are respect, dignity, unbiased information sharing, collaboration, and participation (Johnson, 2012). A review study reported that the key components of pediatric FCC were collaboration of healthcare providers and family members, consideration of policies, procedures, and family backgrounds, and provision of professional education to patients, families, and healthcare providers (Kokorelias et al., 2019). FCC has received great attention in inpatient settings (Hart et al., 2020) and pediatric rehabilitation centers (Frigerio et al., 2022). Its provision in pediatric rehabilitation settings has different positive outcomes such as individualized care provision (Dalvand et al., 2014; Moxley-Haegert, 1983), improvement of parents' daily life skills (Dalvand, Dehghan, Feizy, Amirsalai, & Bagheri, 2009), improvement of children's social interactions (Dalvand, Dehghan, Feizy, & Hosseini, 2009), more active participation of parents in peer groups, reduction of their anxiety (Azari et al., 2019), promotion of mothers' psychosocial well-being, stronger sympathy between families and healthcare providers, and enhancement of their satisfaction with services (Dalvand et al., 2013). Moreover, FCC is effective in adequately fulfilling the healthcare needs of children and families (Khajeh et al., 2017; Kuhlthau et al., 2011; Seliner et al., 2016). On the other hand, lack of FCC provision can reduce care quality, client safety, and family satisfaction (Axelin et al., 2014; Farokhzadian et al., 2021; Parvaneh et al., 2012).

Despite the different positive outcomes of FCC, many structural, organizational, and workforce-related factors can hinder its provision in rehabilitation settings. Examples of structural and organizational factors are poor facilities and physical space (Jalili & Borimnejad, 2020), lack of appropriate places for family education (Rajabi et al., 2016), and lack of written guidelines for FCC provision (Dalvand et al., 2014; Farokhzadian et al., 2021; Riyahi et al., 2019). Workforce-related factors also include poor teamwork, limited managerial support (Antunes & Vaz, 2021; Coyne et al., 2011; Dalvand et al., 2014), and healthcare providers' and family members' inadequate knowledge and skills in terms of the principles of FCC (Almasri et al., 2018; Dalvand et al., 2014; Riyahi et al., 2019).

Although various studies evaluated the influential factors of FCC provision, there is limited information about FCC provision in rehabilitation settings, particularly pediatric rehabilitation settings, in Iran. Thus, the present study was carried out to produce clearer evidence in this area. The aim of the study was to explore the barriers to FCC in the pediatric rehabilitation ward.

## Methods

This descriptive qualitative study was conducted in 2022. Although previous studies assessed FCC in pediatric rehabilitation settings (Antunes & Vaz, 2021; Dalvand et al., 2014; Jeglinsky, 2012; Riyahi et al., 2019; Tew & Ahmad Fauzi, 2020), there is limited information about the barriers to FCC provision to hospitalized CWD. Therefore, the descriptive qualitative design was used in this study for in-depth exploration of the experiences of families' and rehabilitation staff.

### *Ethical considerations*

The Ethics Committee of the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran, approved this study (code: IR.USWR.REC.1400.233). We adhered to the ethical principles of research on human subjects, i.e., confidential data management and voluntariness of participation in and withdrawal from the study. Written informed consent was also obtained from all participants.

### *Participants and setting*

This study was conducted in the pediatric rehabilitation ward of hospital Rofeideh, the only public rehabilitation hospital in Iran. This ward had thirteen beds for the hospitalization of children aged six months to fifteen years. Each child may be hospitalized in this ward once yearly to receive rehabilitation services in three 21-day courses because insurance organizations in Iran covered the costs of hospitalization only for less than 21 consecutive days or less than 63 non-consecutive days per year. Children were discharged from this ward if there was no significant improvement in their conditions during the first 21-day course. Children's mothers could also stay in the ward but there were no facilities for the stay of other family members. Three hundred children were hospitalized each year in this ward. Ward staff included pediatric neurology specialists and subspecialists, six nurses with bachelor's or master's degrees, three nurse aides, and two service workers. Study participants consisted of rehabilitation staff and CWD's mothers. Inclusion criteria were a work experience of at least one year in the pediatric rehabilitation ward for rehabilitation staff, previous history of child hospitalization in the study setting for mothers, and rich care-related experiences in the pediatric rehabilitation ward and consent for participation for all participants. In order to ensure having rich care-related experiences, we selected mothers whose children had been hospitalized in the study setting for at least one 63-day course and had been with their children as caregivers during hospital stay. The rich care-related experiences of rehabilitation staff were also ensured through selecting staff who worked in different work shifts, had a work experience of at least one year (Balbino et al., 2016; Bednarek et al., 2023; Fonseca et al., 2020; Wong et al., 2023), and did not experience organizational turnover during the study. Participants were selected through purposeful and snowball sampling. Purposeful sampling is a widely used technique in qualitative studies to recruit the most appropriate key informants and effectively use limited sources of information (Patton, 2014).On the other hand, snowball sampling is a technique in which each participant introduces the next one (Creswell & Clark, 2017).

### *Data collection*

Data were collected through eleven semi-structured interviews with eleven participants (namely three nurses, one head nurse, one nursing manager, one social worker, and five mothers) and three focus group discussions with twenty participants (namely twelve mothers, four nurses, a physician, a physical therapist, an occupational therapist, and a social worker). Two focus group discussions were held with two six-person groups of mothers and one focus group discussion was held with a six-person group of rehabilitation staff. The aim of holding focus group discussions was to achieve more in-depth data about the barriers to FCC. Questions for the interviews and the focus group discussions were developed based on the principles of FCC (IPFCC, I. f. P.-a. F.-C. C, 2018) (Table 1). Examples of the questions for rehabilitation staff were, "How do you and your colleagues provide care to children and their families in this ward?", "What are the barriers to family care?", and "What components of care are associated with lower participation of families?" Examples of the questions for family members were, "How do you and ward staff give care to your child?", "What are your care-related responsibilities?", "What are the barriers to care?", "What are your expectations of care?", and "What do you mean by the shortage of space and equipment?" Further questions were determined based on participants' responses to the main questions. At the end of the interviews and focus group discussions, participants were asked whether they wanted to

**Table 1**
Semi-Structured Interview Guide based on the principles of FCC: (Participation, Collaboration, Sharing the information, Respect and dignity) (IPFCC, I. f. P.-a. F.-C. C, 2018).

| Interview questions (Rehabilitation Staff/family) |
|---|
| Introductory questions |
| Rehabilitation Staff and family: |
| • What do you think of when you hear the phrase "care with family" instead of "care for family"? |
| General questions |
| Rehabilitation Staff: |
| • How do you deliver care to children and their families in this ward? (Participation/ Collaboration/Respect and dignity) |
| • What are the barriers to family care? (Participation) |
| • What components of care are associated with lower participation of families? (Participation/Collaboration) |
| Family: |
| • How do you provide care for your child? (Participation/Collaboration) |
| • How do ward staff provide care to your child? (Participation/Collaboration) |
| • What are your care-related responsibility? (Participation/Respect and dignity) |
| • What are the barriers to care?" (Participation) |
| • What are your expectations of care? (Respect and dignity) |
| Concluding questions |
| Rehabilitation Staff and family: |
| • Could you share an example from your own experiences with participation problems? |
| • Is there something you would like to add? |
| clarification and probes question |
| Rehabilitation Staff: |
| • "What do you mean by family resistance?" (Participation) |
| • How is the transfer of information about childcare done? (Information sharing) |
| Family: |
| • What do you mean by the shortage of space and equipment? (Respect and dignity) |
| • How is education about your child's condition done? (Information Sharing) |
| Rehabilitation Staff and family: |
| • How have hospital administrators and officials hindered the implementation of family-centered care? (Collaboration) |
| • How have hospital regulations hindered the implementation of family-centered care? (Collaboration) |

add any more point to their shared experiences. On average, the length of the interviews was sixty minutes and the length of the focus group discussions was ninety minutes. Interviews were held in a private room in the study setting at participants' preferred time, while focus group discussions were held in an amphitheater in the study setting at the end of the morning shift. At the time of the interviews with mothers, an auxiliary nurse cared for their children under the supervision of a nurse or the ward head nurse. All interviews and focus group discussions were audio-recorded and the records were transcribed verbatim. Before the interviews, the first author held individualized introduction sessions to inform participants about the study aim and obtain their consent for recording their interviews. All interviews and focus group discussions were held by the first author, while the other authors took notes during sessions and participated in data analysis.

### *Data analysis*

Graneheim and Lundman's conventional content analysis (Graneheim et al., 2017; Graneheim & Lundman, 2004) was used to analyze the data concurrently with data collection. Primarily, interviews were transcribed verbatim and each interview transcript was perused several times to understand its preliminary ideas and the first author wrote the ideas in interpretive notes. All authors independently identified, condensed, and coded meaning units, i.e., sentences and paragraphs that were relevant to the study aim. Then, they compared their codebooks with each other in group sessions, discussed their generated codes to reach an agreement, and grouped the codes into preliminary categories to determine the latent content of the data. Preliminary categories were further developed and grouped into refined main categories. The data were managed using the MAXQDA software (v. 10.0) which is used for the management of textual and multimedia data (GmbH., M.-D. b. V., 2023).

### *Trustworthiness*

Trustworthiness was established through Lincoln and Guba's criteria, namely credibility, dependability or accountability, confirmability, transferability, and authenticity (Lincoln, 1985; Polit & Beck, 2008).

Credibility refers to the confidence in the accuracy of the data and their interpretations, dependability refers to the stability of the data over time and conditions, confirmability refers to the objectivity of the findings or the congruence between participants' experiences and the findings, transferability refers to the ability to transfer the findings to other settings or groups, and authenticity improves readers' understanding of the intended phenomenon (Polit & Beck, 2008). Credibility was ensured using an interview guide (which helped ensure the coverage of all aspects of the intended phenomenon during data collection), close relationships with participants, member checking, and peer checking. Member checking was used to ensure that the findings reflected participants' experiences and views rather than researchers' knowledge and experiences (Birt et al., 2016; Tong et al., 2007). For the member checking of the findings of the interviews, several interviewees assessed and confirmed the congruence between their own experiences and the results of the interview data analysis. For the member checking of the findings of the focus group discussions, the findings of a focus group discussion were provided to six participants during a single session, where they independently assessed and confirmed the congruence between the findings and their shared experiences (Birt et al., 2016; Tong et al., 2007). Dependability was ensured through collaborative data analysis by all authors and careful documentation of all steps of the study. Confirmability was established through external peer debriefing and also by presenting data-based findings through providing direct quotations of participants' shared experiences. In external peer debriefing, two experienced qualitative researchers and two PhD nursing students assessed and confirmed the accuracy of data analysis. Transferability was also ensured through providing clear descriptions about participants' characteristics, sampling, and context as well as through sampling with maximum variation respecting rehabilitation staff's age, gender, educational level, organizational position, and work experience and mothers' age, educational level, occupation, place of residence, length of hospital stay, and type of child disability. Finally, authenticity was achieved through working as close as possible to the data with a degree of abstraction and interpretation in order to produce meaningful and understandable findings. Moreover, the consolidated criteria for reporting qualitative research (COREQ) were used to ensure the explicit and comprehensive reporting of the data (Tong et al., 2007).

## Results

Most participating staff and mothers were married (55.5% vs. 100%), most staff had bachelor's degree (66.6%), and most mothers had diploma (58.3%). The means of participants' age was 35.7 years in total, 37.3 years for staff, and 34.66 years for mothers (Tables 2 and 3). The mean of mothers' hospital stay was 51.3 days and the mean of staff's work experience was 7.5 years. The barriers to FCC in the pediatric rehabilitation ward were organized into three main categories, namely family-related barriers, staff-related barriers, and organizational barriers (Table 4).

**Table 2**
Participants' characteristics.

| No. | Participant type | Gender | Age (Years) | Marital status | Organizational position | Work experience or ward stay | Educational degree | Data collection method |
|---|---|---|---|---|---|---|---|---|
| 1 | Staff | Female | 38 | Single | Social worker(p1) | 8 years | Bachelor's | Interview and FGD |
| 2 | Staff | Female | 34 | Married | Nurse(p2) | 3 years | Master's | Interview and FGD |
| 3 | Staff | Female | 38 | Married | Nurse(p3) | 5 years | Master's | Interview and FGD |
| 4 | Staff | Female | 29 | Single | Nurse(p4) | 5 years | Bachelor's | Interview |
| 5 | Staff | Female | 34 | Single | Head nurse(p5) | 8 years | Bachelor's | Interview and FGD |
| 6 | Staff | Female | 46 | Married | Nursing manager(p6) | 16 years | Bachelor's | Interview and FGD |
| 7 | Staff | Male | 45 | Married | Medical specialist(p7) | 18 years | Pediatric neurologist | FGD |
| 8 | Staff | Female | 37 | Single | Physical therapist(p8) | 3 years | Bachelor's | FGD |
| 9 | Staff | Female | 35 | Single | Occupational therapist (p9) | 2 years | Bachelor's | FGD |
| 10 | Parent | Female | 32 | Married | — (f1) | 38 days | Diploma | Interview and FGD |
| 11 | Parent | Female | 27 | Married | — (f2) | 60 days | Diploma | Interview and FGD |
| 12 | Parent | Female | 43 | Married | — (f3) | 45 days | Diploma | Interview and FGD |
| 13 | Parent | Female | 30 | Married | — (f4) | 60 | Diploma | Interview and FGD |
| 14 | Parent | Female | 41 | Married | — (f5) | 30 days | Bachelor's | Interview and FGD |
| 15 | Parent | Female | 34 | Married | — (f6) | 50 days | Bachelor's | FGD |
| 16 | Parent | Female | 45 | Married | — (f7) | 70 days | Below diploma | FGD |
| 17 | Parent | Female | 30 | Married | — (f8) | 30 days | Diploma | FGD |
| 18 | Parent | Female | 38 | Married | — (f9) | 63 days | Below diploma | FGD |
| 19 | Parent | Female | 37 | Married | — (f10) | 60 days | Bachelor's | FGD |
| 20 | Parent | Female | 34 | Married | — (f11) | 63 days | Diploma | FGD |
| 21 | Parent | Female | 27 | Married | — (f12) | 47 days | Diploma | FGD |

FGD: Focus group discussion.

**Table 3**
Descriptive statistics of demographic variables.

| Staff | N(%) | Mean(SD) | Range | Total |
|---|---|---|---|---|
| Age | 9(100%) | 37.33(5.077) | 29–46 | |
| Work experience (years) | 9(100%) | 7.55(5.43) | 2–16 | 68 |
| **Gender** | | | | |
| Male | 1(11.1%) | | | |
| Female | 8(88.8%) | | | |
| **Marital status** | | | | |
| Single | 5(55.5%) | | | |
| Married | 4(44.44%) | | | |
| **Organizational position** | | | | |
| Nurse | 5(55.5%) | | | |
| Social worker | 1(11.1%) | | | |
| Medical specialist | 1(11.1%) | | | |
| Physical therapist | 1(11.1%) | | | |
| Occupational therapist | 1(11.1%) | | | |
| **Educational degree** | | | | |
| Pediatric neurologist | 1(11.17%) | | | |
| Master's | 2(22.22%) | | | |
| Bachelor's | 6(66.6%) | | | |
| Parent | N(%) | Mean(SD) | Range | total |
| Age | 12(100%) | 34.66(5.78) | 27–45 | |
| Ward stay (day) | 12(100%) | 51.33(13.38) | 30–70 | 616 |
| **Gender** | | | | |
| Male | 0(0%) | | | |
| Female | 12(100%) | | | |
| **Marital status** | | | | |
| Single | 0(0%) | | | |
| Married | 12(100%) | | | |
| **Educational degree** | | | | |
| Bachelor's | 3(25%) | | | |
| Diploma | 7(58.3%) | | | |
| Below diploma | 2(16.66%) | | | |

*Family-related barriers*

Family in this study referred to the individuals who had the custody of the child and were with the child during the process of rehabilitation. Family was the core of FCC in the study setting. The subcategories of this category were family's knowledge about child rehabilitation, family's sociocultural background, and family's participation.

*Family's knowledge about child rehabilitation*

Participants noted that some families had limited knowledge about their child's disease and its complications due to their low educational level, poor relationships with healthcare providers, poor information exchange with healthcare providers, inability to express their educational needs, and lack of appropriate and timely family education by healthcare providers. On the other hand, the higher educational level of some families was associated with their greater desire for establishing relationships with healthcare providers and exchanging information with them. Participants highlighted that healthcare providers in the study setting needed to keep some families with low educational level in their ward in order to improve their child rehabilitation knowledge and skills and improve FCC.

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**Table 4**
Main Categories and Subcategories of Family Centered Care (FCC) Barriers in Pediatric Rehabilitation Ward.

| Main Categories | Subcategories | Codes | Meaning Units | Quotes |
|---|---|---|---|---|
| Family-Related Barriers | Family Knowledge about Child's Rehabilitation | Insufficient Family Knowledge | Little and Inaccurate Information about Care | Families that refer to this hospital for the first time have little and inaccurate information about care but receive education during their hospital stay and develop their care-related knowledge and skills. (P. 3). |
| | Family's Sociocultural Background | Cultural Diversity | Special Beliefs and Cultural Diversity | Patients in this ward are mostly from towns with limited rehabilitation facilities and have special beliefs. This faces nurses and other rehabilitation staff with a cultural diversity that necessitates bilateral coping (P. 5). |
| | Family's Participation | Family Resistance to Staff Recommendations | Failure to Change Previous Care Methods by Family | "The staff said (P.5), quoting from the mother: 'that my method for feeding my child is wrong but it is for six years that I have fed my child with this method. I know my child better than anyone. During my child's hospital stay, feeding is perhaps the only thing I can do for my child and I don't change it'" (F. 5). |
| Staff-Related Barriers | Staff's Knowledge | Inadequate Professionalism | Staff lack Awareness of their Role and the Importance of FCC | Staff are unaware of their role and the importance of FCC for patients with chronic illnesses and do not make any effort to improve their knowledge. Their practice is based solely on their little FCC-related materials they learned during their university education. Therefore, we provide FCC based on experience and each staff acts based on his/her approach. Sometimes, some colleagues think that their practice is completely family-centered and there is no need for change (P. 5). |
| | Staff's Ethical Concerns | Negative Emotions, Beliefs, and Attitudes | Efforts in the Hospital are Considered Futile and Exhausting | We sent the mother to a hospital unit to receive financial support. The staff had limited collaboration and inappropriately treated the mother. This undermined the mother's morale and reduced her collaboration with us. This shows that some colleagues do not accurately perform their tasks and do not solve the problems of the patient or the system. They believe that efforts are futile and tiresome because patients in rehabilitation centers do not achieve recovery (P. 3). Some staff insist on the child discharge instead of helping families (P. 3). |
| | Collaboration among Staff | Poor Teamwork Morale | Teamwork Morale is low among the Staff | Teamwork morale is poor among the staff. For example, although my colleague sees I have a heavy workload, she just performs her tasks and then, takes a rest instead of helping me (P. 3). |
| Organization Barriers | Factors Related to FCC Policies | Lack of Family-Centered Care Guidelines | Absence of a coherent policy for FCC | FCC is an important part of care for children with chronic illnesses who need rehabilitation. However, there is no coherent policy for FCC provision and each of the staff acts based on his/her personal experience. We do not know how much accurate our performance is. Guidelines and evaluation tools can guide and coordinate our practice (P. 2). |
| | Managerial Factors | Unfair Management | Hospital Rules Lack Fairness | Unlimited family-patient visitation is one of the prerequisites to FCC provision in the pediatric rehabilitation ward. However, hospital rules and regulations are identical for all wards and there is no unlimited family-patient visitation policy in the pediatric rehabilitation ward. The security staff of the hospital do not allow family members to visit their children outside the visitation time and this has caused family dissatisfaction (P. 3). |
| | Environmental Factors | Inadequate Space | Limited Family Accommodation | This hospital lacks a place for family residence and fathers have no permission to stay with their families. In certain cases, a hotel room is allocated to some fathers at their expense (P. 1). The design of this ward is inappropriate for the pediatric ward and FCC. The ward space is so small that mothers have inadequate space for changing and keeping clothes (P. 2). |
| | Factors Related to the COVID-19 Pandemic | Restrictions on Routine Care | COVID-19's Impact on Care | COVID-19 affected all aspects of care, including regulations. Currently, we have restrictions on hospitalization and visitation. Before the COVID-19 pandemic, we visited and assessed other family members during visitation time and answered their questions. However, we currently have direct contact only with children and this has limited our relationships with families (P. 6). |

Participants highlighted that healthcare providers in the study setting needed to keep some families with low educational level in their ward in order to improve their child rehabilitation knowledge and skills and improve FCC.

> *Families that refer to this hospital for the first time have little and inaccurate information about care but receive education during their hospital stay and develop their care-related knowledge and skills. Thus, their knowledge and skills at hospital discharge are very different from their knowledge and skills at hospital admission. It seems that attending hospital and receiving education are effective in improving parents' skills and participation [in care] (P. 3).*

However, some participants reported that some educations were incongruent with families' educational needs.

> *I had stress when I came here. They provided me with educations in the first day, but I didn't learn anything and I didn't tell anything about my unreadiness for receiving educations. However, I felt needed to continuously ask questions. When I came here for the second time, they repeated the previous educations and I felt that most of the provided educations were repetitive. I would have received more effective educations if I had told them about my educational needs or if they had asked me about my educational needs (F. 4).*

*Family's sociocultural background*

Participants' experiences showed that families' special beliefs and values, such as patriarchy, can affect FCC in the pediatric rehabilitation ward. They stated that some patients referred to rehabilitation settings from other towns and hence, their beliefs and values were different from those of healthcare providers. Sometimes, such difference caused problems in FCC provision. For examples, some mothers reported that they were unable to understand some explanations provided by healthcare providers. Therefore, they highlighted the necessity of assessing the sociocultural beliefs of patients and families and values and developing socio-culturally appropriate care plans.

> *Patients in this ward are mostly from towns with limited rehabilitation facilities and have special beliefs. This faces nurses and other rehabilitation staff with a cultural diversity that necessitates bilateral coping. Otherwise, healthcare providers cannot establish effective relationships with patients and families and this may lead to families' resistance against FCC and their misunderstanding of healthcare providers' explanations. Moreover, men in some families don't consent for their children's hospitalization or their wives' stay in this hospital because they think this may cause problems for them. Sometimes, a man may threaten his wife with the possibility of his second marriage and hence, the woman stops her child treatment and returns home. All these problems are due to families' cultural background (P. 5).*

*Family's participation*

An essential prerequisite to effective FCC in rehabilitation settings is the active participation of family members in child rehabilitation. Participants highlighted that some families had poor participation due to different factors such as the long-term course of disability, prolonged hospital stay, separation of family members from each other, as well as parents' reluctance to join peer groups, reduced motivation, disappointment, fatigue, and resistance to healthcare providers' recommendations.

> *"Staff said (P.5) 'that my method for feeding my child is wrong but it is for six years that I have fed my child with this method. I know my child better than anyone. During my child's hospital stay, feeding is perhaps the only thing I can do for my child and I don't change it' (F. 5).*

> *'I have no desire for membership in family groups because talking with others does not solve any problem. Some people may like confabulation; but it's for 32 days that I'm listening. I'm tired and have no more mood for talking with others'" (F. 1).*

## Staff-related barriers

Participants considered some staff-related factors as barriers to FCC in the pediatric rehabilitation ward. The three subcategories of this category were staff's knowledge, staff's ethical concerns, and collaboration among staff.

*Staff's knowledge*

Most healthcare providers in the study setting had limited professional knowledge about FCC and provided FCC rehabilitation services based on their own experiences.

> *Staff are unaware of their role and the importance of FCC for patients with chronic illnesses and do not make any effort to improve their knowledge. Their practice is based solely on their little FCC-related materials they learned during their university education. Therefore, we provide FCC based on experience and each staff acts based on his/her approach. Sometimes, some colleagues think that their practice is completely family-centered and there is no need for change (P. 5).*

*Staff's ethical concerns*

Staff's ethical concerns were mainly due to problems in their professional conscience and their negative emotions, beliefs, and attitudes towards FCC. Moreover, participants noted that the chronicity of children's disabilities, their prolonged hospital stay, and limited improvement in their conditions caused fatigue for rehabilitation staff and reduced their ability to effectively perform their roles.

> *One of the families could not pay the costs of hospitalization. We sent the mother to a hospital unit to receive financial support. However, the unit staff had limited collaboration with us and inappropriately treated the mother. This undermined the mother's morale and reduced her collaboration with us. This shows that some colleagues do not accurately perform their tasks and do not solve the problems of the patient or the system. They believe that efforts are futile and tiresome because patients in rehabilitation centers do not achieve recovery(P. 3).*

*Collaboration among staff*

Staff in the study setting worked based on the task-based approach, had limited motivation, suffered from fatigue, and were reluctant to actively engage in teamwork.

> *Teamwork morale is poor among the staff. For example, although my colleague sees I have a heavy workload, she just performs her tasks and then, takes a rest instead of helping me. Of course, this has many different reasons, the most important of which is job burnout. Job burnout negatively affects our collaboration because insignificant improvement in patients' conditions wastes our energy and nobody has the energy to organize a team to follow children's care plan. The head nurse also fills the forms alone. On the other hand, in response to families' resistance, some staff insist on the child discharge from the hospital instead of helping families and gaining their trust in teamwork (P. 3).*

## Organizational barriers

Some organizational factors acted as barriers to FCC in the pediatric rehabilitation ward. These factors were factors related to FCC policies, managerial factors, environmental factors, and factors related to the coronavirus disease 2019 (COVID-19) pandemic.

*Factors related to FCC policies*

Despite the importance of coherent FCC policies for effective FCC in pediatric rehabilitation settings, these policies were not available in the study setting. Therefore, the staff provided FCC based on their personal experiences. Moreover, there were no in-service FCC-related educational programs for the rehabilitation staff in the study setting and hence, they had limited FCC-related knowledge and skills.

> *FCC is an important part of care for children with chronic illnesses who need rehabilitation. However, there is no coherent policy for FCC provision and each of the staff acts based on his/her personal experience. We don't know how much accurate our performance is. Guidelines and evaluation tools can guide and coordinate our practice (P. 2).*

*Managerial factors*

Most organizational rules and regulations, which were determined by the dean and the nursing managers of the study setting, were inflexible and were associated with staff dissatisfaction. Nonetheless, managers believed that the enactment of specific rules and regulations for the pediatric rehabilitation ward, which were different from the rules and regulations of other hospital wards, could cause inconsistencies in

the hospital. Moreover, given the availability of different wards in the rehabilitation hospital, the pediatric rehabilitation ward was not the top priority of the managers. These factors reduced the motivation of the pediatric rehabilitation staff and negatively affected FCC in the pediatric rehabilitation ward.

*Unlimited family-patient visitation is one of the prerequisites to FCC provision in the pediatric rehabilitation ward. However, hospital rules and regulations are identical for all wards and there is no unlimited family-patient visitation policy in the pediatric rehabilitation ward. The security staff of the hospital don't allow family members to visit their children outside the visitation time and this has caused family dissatisfaction (P. 3).*

*Nursing managers don't appreciate ward staff and transfer staff with great motivation from the pediatric ward to other wards without consulting them. This has reduced staff's motivation.*

### *Environmental factors*

Although an appropriate environment can facilitate FCC provision, participants reported that patients and families experienced considerable stress in the study setting. The main stressors in the study setting for patients and families were the poor design of the pediatric rehabilitation ward, lack of equipment, lack of a place for family residence, inadequate space to maintain child and mother privacy, and large number of patients and companions in ward rooms.

*This hospital lacks a place for family residence and fathers have no permission to stay with their families. In certain cases, a hotel room is allocated to some fathers at their expense (P. 1).*

*The design of this ward is inappropriate for the pediatric ward and FCC. The ward space is small with limited number of rooms. Nonetheless, the rest room of the supervisor is in this ward. We have to use the children's play room as a rehabilitation room. The ward space is so small that mothers have inadequate space for changing and keeping clothes. Therefore, we inform families to bring little items with them despite their long stay here (P. 2).*

### *Factors related to the COVID-19 pandemic*

Organizational rules and regulations for COVID-19 management in the study setting negatively affected the relationships between staff and families, family education, and participation of family members in the process of care. Families' reluctance to hospitalize their children in the pediatric rehabilitation ward due to their fear over affliction by COVID-19 also negatively affected children's rehabilitation and recovery. On the other hand, families had to pay extra costs to buy personal protective equipment and faced restrictions in visiting their children. The rehabilitation staff also experienced increased workload, added physical and mental strain, and lack of personal protective equipment. Moreover, hospital managers had to make rapid decisions and frequently change policies and regulations.

*COVID-19 affected all aspects of care, including regulations. Currently, we have restrictions on hospitalization and visitation. Before the COVID-19 pandemic, we visited and assessed other family members during visitation time and answered their questions. However, we currently have direct contact only with children and this has limited our relationships with families (P. 6).*

*COVID-19 added a new pain to our pains (F 4).*

## Discussion

This study explored the barriers to FCC in the pediatric rehabilitation ward. These barriers came into three main categories, namely family-related barriers, staff-related barriers, and organizational barriers.

Findings revealed family's lack of knowledge about child rehabilitation as one of the family-related barriers to FCC in the pediatric rehabilitation ward so that families needed education about child rehabilitation. In agreement with this finding, previous studies reported that families needed education about care provision to CWD (Antunes & Vaz, 2021; Dalvand et al., 2014; Schenker et al., 2016). The needs of the families of CWD seem to be different from the needs of the families of other children due to the long-term course of their children's disability. The problems of these families in care provision aggravate with child age and hence, they need to receive quality need-based education in order to provide accurate FCC and have more active participation in the process of care (Hockenberry & Wilson, 2018).

Family's poor participation in the process of rehabilitation was another family-related barrier to FCC. Most families preferred their own caregiving methods and hence, resisted adherence to the recommendations of rehabilitation staff and FCC. The parents of CWD provide care to their children for long periods of time and choose their own caregiving methods. Therefore, they may resist changing their methods even if they are incorrect and have potential risks to their children (Shelton, 1987).

A study also reported that some families may think they are expected to develop their care-related knowledge beyond their abilities and hence, may experience stress and show resistance (Watts et al., 2014).

The difference between the sociocultural backgrounds of families and rehabilitation staff was another family-related barrier to FCC in the pediatric rehabilitation ward. Cultural factors are among the influential factors of FCC (Boztepe & Kerimoğlu Yıldız, 2017; Srivastava, 2014). Therefore, close attention to cultural issues and assessment of families' needs are among the essential components of FCC (Houtrow, 2019; Khajeh et al., 2017; Shelton, 1987; Vasli, 2021).

The second main category of the barriers to FCC in the pediatric rehabilitation ward was staff-related barriers. Staff's limited professional knowledge and their ethical concerns were among these barriers. Staff's knowledge and commitment respecting FCC are factors with significant effects on FCC (Antunes & Vaz, 2021; Boztepe & Kerimoğlu Yıldız, 2017). Our findings showed that staff with greater FCC-related knowledge and ethical concerns had greater motivation to develop their knowledge and provide education to families, while some staff had limited understanding about the importance of FCC and hence, had limited motivation for developing their FCC-related knowledge and providing FCC-related education to families. Similarly, previous studies showed that staff had moderate knowledge about the principles of FCC and hence, provided poor education to families (Coyne et al., 2011; Riyahi et al., 2019).This can be attributed to the lack of FCC-related education for the rehabilitation staff (Dalvand et al., 2014; Kuo et al., 2012; Riyahi et al., 2019).

Lack of collaboration among rehabilitation staff was the other staff-related barrier to FCC in the present study. Besides great FCC-related knowledge, rehabilitation staff need close interprofessional collaboration (Dalvand et al., 2014; Mazer et al., 2006). However, our findings revealed that staff's paternalistic approach to care that ignored patient and family preferences as well as their limited motivation to work in the pediatric rehabilitation ward negatively affected their teamwork. In agreement with our findings, a study reported paternalism in healthcare systems as a barrier to FCC (Dalvand et al., 2014). Another study showed that lack of financial incentives and benefits limited staff's motivation for FCC provision (Abraham & Moretz, 2012). Moreover, staff shortage can increase nurses' workload and reduce their motivation for FCC (Seyedfatemi et al., 2020; Vasli, 2021).

The third main category of the barriers to FCC in the pediatric rehabilitation ward was organizational barriers. One of these barriers was the lack of clear FCC-related policies and guidelines. Several previous studies in Iran also showed the lack of written guidelines for FCC in pediatric hospitals (Dalvand et al., 2014; Farokhzadian et al., 2021; Riyahi et al., 2019; Seyedfatemi et al., 2020) which can be due to the

poor understanding of healthcare authorities and staff about the importance of FCC for pediatric rehabilitation (Dalvand et al., 2014). FCC provision is associated with many different positive outcomes (Antunes & Vaz, 2021; Kokorelias et al., 2019) and hence, strategies are necessary to facilitate it in pediatric rehabilitation settings. Managerial factors were also among the organizational barriers to FFC in the present study. Examples of these factors were mandatory staff transfer to other wards and limited incentives and support for them which were associated with their reduced motivation for FCC. Previous studies also reported the same finding and highlighted the necessity of greater managerial attention and support for nurses (Antunes & Vaz, 2021; Lotze et al., 2010).

Study findings also indicated that another organizational barrier to FCC was inflexible organizational rules and regulations, such as restricted family visitation policy, which were associated with family and staff dissatisfaction as well as problems in FCC provision. Inflexible regulations can limit parents' attendance at their children's bedside (Mirlashari et al., 2020), limit staff's role performance (Dalvand et al., 2014; Riyahi et al., 2019; Vasli, 2021), and lead to staff dissatisfaction and sense of worthlessness (Litchfield & MacDougall, 2002). In line with our findings, poor organizational policies and regulations were the most important barriers to FCC in two previous studies (Braga et al., 2005; Braga & da Paz, 2006). A flexible organizational culture can facilitate teamwork (Hostler, 1991) and hence, is essential to FCC in rehabilitation settings.

Study findings also revealed environmental factors such as inadequate physical space for family residence, family education, and family privacy as barriers to FCC. In agreement with our findings, several previous studies reported lack of adequate space in inpatient settings (Frakking et al., 2020; Malepe et al., 2022), lack of space to maintain patient privacy, and lack of beds and chairs in clinical settings (Lloyd et al., 2018). The families of hospitalized children in pediatric rehabilitation settings have long hospital stay and hence, the environment of these settings should be pleasant (Frakking et al., 2020; Malepe et al., 2022; Taghipour, 2021). The hospital environment should be developed based on patients' and families' needs (Taghipour, 2021) and hospital policies should facilitate their participation in the process of care and families' access to patients (Choi & Bosch, 2013). A good physical environment in hospitals promotes relationships and improves the safety of patients, families, and healthcare providers (Rippin et al., 2015; Smith, 2018). A hospital environment that is designed for FCC can enhance family satisfaction and engagement in the process of care.

We also found organizational policies for COVID-19 prevention and management as a barrier to FCC in the pediatric rehabilitation ward. Some families avoided hospitalizing their children in the study setting due to their fear over affliction by COVID-19 or their inability to have personal protective equipment. The sudden global outbreak of COVID-19 was associated with changes in FCC provision policies (Bamir & Sadeghi, 2020; Kutsar & Kurvet-Käosaar, 2021). A study recommended tele-rehabilitation to maintain the continuity of rehabilitation services and overcome hospitalization-related fear during the COVID-19 pandemic (Frigerio et al., 2022). Two other studies highlighted that the advantages of parents' attendance at clinical settings are far beyond the risk of affliction by COVID-19 and hence, recommended face-to-face care provision (Al-Motlaq et al., 2021; Pollock et al., 2022). Healthcare managers need to develop effective strategies to maintain the continuity of FCC in all conditions, including epidemic conditions.

### *Limitations and strengths*

This study was conducted on a small sample and in a hospital setting and hence, its findings may not widely be transferable. Moreover, only mothers could stay with their CWD in the study setting due to the COVID-19 pandemic and the lack of appropriate facilities and hence, we could not explore the experiences of children's fathers. Besides, some participants might have been reluctant to freely share some aspects of their experiences in focus group discussions. Of course, we attempted to overcome this limitation through holding individual interviews with most participants in focus group discussions.

Among the strengths of this study were data collection through both interviews and focus group discussions and exploration of the experiences of both parents and rehabilitation staff. Moreover, this study was conducted in a leading university-affiliated rehabilitation hospital. It also provided in-depth information about the cultural and sub-cultural aspects of FCC and its findings may be applicable to different populations.

### *Implications to practice*

The results of this study can help clinical managers develop clear guidelines for quality FCC provision to CWD in rehabilitation settings. Researchers can also use the findings to conduct ethnographic studies into the culture of these children and their families.

## Conclusion

This study shows that there are different family-related, staff-related, and organizational barriers to FCC in pediatric rehabilitation settings. Given the prolonged attendance of family members at pediatric rehabilitation settings, FCC is an essential component of quality pediatric rehabilitation and hence, strategies are essential to remove its barriers and facilitate its quality provision. Examples of these strategies are improvement of managers' performance, provision of stronger managerial support to FCC rehabilitation staff, implementation of FCC-related educational programs for rehabilitation staff, improvement of the environment of pediatric rehabilitation settings, enhancement of rehabilitation staff's motivation for FCC, and conducting further studies into the best interventions for identifying and removing the barriers to FCC in pediatric rehabilitation settings.

## Data accessibility statement

The main data of the study are available in this manuscript. Further data can be accessed through contacting the corresponding author.

## Author contribution

All authors engaged in designing the study and drafting this manuscript. TN performed data collection and analysis.

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## Declaration of Competing Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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