

Preference of the patient's family for family-centred care in a paediatric hospital

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Abstract

Objective: To explore the dimensions of family-centred care preferred by families of paediatric inpatients in a public healthcare setting.

Method: The qualitative study was conducted at the National Institute of Child Health, Karachi, from October 2021 to August 2022, and comprised family members of the hospitalised children. Data was collected through three focus group discussions that were guided by a semi-structured questionnaire. Using the five-step Fereday and Muir-Cochrane guidelines, data was coded and subjected to thematic analysis.

Results: Of the 21 subjects, 13(62%) were males and 8(38%) were females. The overall mean age was 32.24±7.58 years (range: 18-50 years). In terms of relationship with the patient, 9(43%) were fathers and 6(28.6%) were mothers. Each focus group discussion had 7(33.3%) subjects. Thematic analysis showed that the participants perceived family-centred care positively. Eight categories emerged depicting family perception and experience of family-centred care in a tertiary-care setting.

Conclusion: The participants perceived family-centred care respectful and empathic towards patients' families, making them integral care team members.

Keywords: Delivery of health care, Paediatrics, Personal satisfaction, Parents, Family, Patient-centred care.

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Introduction

A family is the natural and fundamental unit of society which encompasses blood relatives like parents, siblings, children and relations by marriage. A family plays a crucial role in all aspects of a child's life, especially when contemplating a child's health. Children generally depend on their parents, who are experts on their illness experience, and advocate on their behalf, so a partnership between parents, family and healthcare providers are unavoidable, especially in the domain of paediatrics.^{1,2}

Any illness in a child disturbs the whole family. Every individual family is unique in its perceptions and dynamics, its potential to adapt to underlining stress, and strategies to reintegrate. This demeanour needs to be acknowledged and appropriately addressed by the health professionals. A lack of communication with healthcare professionals is a source of substantial stress for families of sick children, who prefer the human qualities of a healthcare provider, such as empathy and sensitivity, over their technical competence. Thus, making it indispensable for healthcare

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professionals to include parents as equal partners in planning care around a sick child.^{3,4}

With the advancement in medicine, children with chronic problems are surviving to a usual life span, thus shifting caregiving responsibility on to parents and families. Consequently, the objective of the health system has also evolved from merely providing curative treatment to providing emotional support, remediation and improving health-related quality of life. Thus, the concept of family-centred care (FCC) originated and developed over time with the idea of recognising parents and family members of sick children as care recipients and considering them equal partners in patient care and decision-making.^{5,6}

FCC is a revolutionary approach to planning and administering healthcare to sick children that identify parents as experts on the needs of their children. It is a philosophy grounded in mutually beneficial partnerships among patients, families and healthcare givers to support a family. It has evolved as a multidisciplinary approach addressing the family's physical, psychological, social and emotional needs.^{4,7,8} FCC has attained universal acceptance in paediatrics as the gold-standard caring model targeting the patients, their families and healthcare givers. In this approach, families determine how they wish to participate in the care while endorsing physicians support the parents, respectfully sharing information, and giving them control over decision-making.^{9,10}

In the mid-20th century, when paediatric hospitals had a strict visiting policy not allowing parents to stay with their children, Carl Rogers proposed the concept of client-centred care (CCC) as a novel idea in psychotherapy. The family advocacy movements upheld this notion by insisting on the family importance for the wellbeing of hospitalised children, particularly in the context of children with special needs, thus proposing a care model in which families could work in partnership with healthcare professionals.^{11,12} The Picker Institute coined the term patient-centred care (PCC), highlighting patient integrity and proposing 8 principles; respect, information-sharing, family involvement, physical comfort, emotional support, access to care, coordination, integration of care, and transition and continuity.⁵ The FCC got a legislative mandate in the United States, granting legal power to the families of children with special needs and making them equal partners in healthcare. Subsequently, the Association for the Care of Children Health (ACCH) laid down essential elements of FCC, endorsing it as the best care model for hospitalised children and their families.¹³

Aiming to promote FCC, the Institute for Patient and Family-Centred Care (IPFCC) was founded with a vision to integrate the FCC concepts into all aspects of healthcare with an ongoing partnership involving patients, families and healthcare providers, and reducing restrictions on the family presence, thus upgrading a family's status from mere visitors to equal care partners to improve the quality and outcomes.¹³ The IPFCC described the principal FCC components as dignity and respect, information-sharing, family participation in care and decision-making, and collaboration between healthcare practitioners and families in implementing policy and programmes.^{1,14}

The ACCH defined elemental constituents of the FCC as: to recognise the family as the constant in a child's life, acknowledge the family's uniqueness and methods of coping, recognise the parents as experts in child care and share unbiased information with them, to understand the age-appropriate needs of children and incorporate them into healthcare, to facilitate a collaborative relationship between parents and professionals, to implement appropriate policies and programmes to promote family-to-family support, to provide emotional and financial support to the families as per their needs, to modify the healthcare system to make it accessible and responsive to family needs, and to implement appropriate policies to meet the needs of staff members.^{1,9,15}

There is evidence of positive FCC outcomes for children, families and healthcare providers. The advantages for the patient are accelerated recovery, reduced pain and anxiety, decreased length of hospital stay, and improved health

outcomes.^{16,17} Empowering parents in child care increases their knowledge and caregiving skills, resulting in a superior care experience and more appropriate decision-making, decreased misunderstanding, family satisfaction, and an improved psychological and physical quality of life. Similarly, the healthcare providers have the benefits of reduced stress, higher confidence and job satisfaction, and improved quality of care.^{11,18,19}

The FCC model has gained recommendation and endorsement from leading child health promoters, such as the American Academy of Paediatrics (AAP), the Maternal and Child Health Bureau (MCHB), and the National Association of Children's Hospital and Related Institutions (NACHRI). The model has been internationally adopted by most developed countries, while gaining acceptance in many developing and South Asian countries.^{5,9}

Pakistan, a developing country, is the 5th largest in terms of population. In Pakistan, the family is the centre of existence, people prefer to live in extended families with strong family bonds, and family relationships are both horizontal and vertical. In medical decision-making, the family has a primary role. The idea of FCC is still naive in the region, and local data is scanty. Upon literature review, only a few studies could be found, including Ladak et al. who studied the preference of Pakistani parents for family-centred rounds, recognising it as a source of satisfaction for parents and improving the quality of care. Bhutta et al. reported that the mother's participation in the care of low birth weight infants was associated with a decreased rate of infection, decreased hospital stay, and early discharge.^{17,20}

Although the FCC concept has gained global acceptance, there is still a paucity of data outside the Western context, and the experience of parents and families of children hospitalised in public hospital has not been explored. The current study was planned to explore the dimensions of FCC preferred by families of paediatric inpatients in a Pakistani public healthcare setting.

Subjects and Methods

The qualitative study was conducted at the National Institute of Child Health (NICH), Karachi, from October 2021 to August 2022, after approval from the institutional ethics review board. The NICH is a 500-bed tertiary-care hospital, which is the largest paediatric teaching hospital, and a primary referral point. The sample was raised using purposive sampling technique. Those included were parents and family members aged > 18 years of children admitted in any ward or intensive care unit (ICU) who had accompanied their hospitalised child. Those unable to understand or speak the Urdu language, and attendants of

patients having 'do-not-resuscitate' (DNR), 'do not intubate' (DNI), or 'no code' advice were excluded.

Data was collected through focussed group discussions (FGDs) after taking written informed consent from all the participants, including the permission to audio-record the sessions. The participant's identity remained concealed throughout the study, and any identifying features in the data was removed. The focus group moderator verbally explained the goals and objectives of the research ahead of the discussion, additionally providing them with handouts in Urdu that contained information about the study, about their roles and responsibilities, and regarding general instructions on how to interact with other group members while maintaining integrity and respect. The queries and concerns of the participants were responded to before the formal commencement of the interview.

The rationale for employing FGDs for data collection was to obtain a detailed insight into the family's perceptions and experiences of the FCC. A total of 3 FGDs were conducted in a non-clinical area, and each discussion lasted about 90 minutes.

A proforma was employed to obtain the socio-demographic information. A moderator led the FGDs, using appropriate probes to elicit in-depth detail. An assistant moderator contributed to the audio recording of the session, maintaining the audit trail and documenting the verbal and nonverbal cues during communication. A semi-structured interview questionnaire with open-ended questions guided the FGDs (Table 1). The interviews took place in Urdu. Each interview was audio-recorded, transcribed verbatim, and translated into English by a professional translator with a medical background. All the transcripts were compared with the audio recordings to ensure data credibility. The principal investigator verified and validated the translated transcripts to minimise

Table-1: The semi-structured questionnaire guiding the focus group discussion (FGD) sessions.

Q	Why is your child hospitalized, and what is your experience during the hospital stay?
Q	What went well, and what could have been done better?
Q	How do you evaluate the behaviour of doctors and nurses during hospitalization?
Q	How frequently do you feel welcomed or cared for by hospital staff (including doctors and nurses)?
Q	How frequently do you feel yourself a valued team member when planning your child's care? Please elaborate.
Q	Have you ever been included in the procedures on your child (like cannula, blood sampling, NG, catheterization, or lumbar puncture etc.)? Or have you ever wished to be present during any procedure?
Q	Are you satisfied with the quality of family-centred care provided in the hospital? Please specify your answer.
Q	Given your experiences, what could have been done better for families while providing health care to the child?
Q	Out of all the things discussed, what is the most important?

language-related errors.

Data collection and analysis occurred iteratively to identify the emerging categories. The five-step Fereday and Muir-Cochrane²¹ guidelines were used to process, data coding and thematic analysis. The authors went through the transcripts line-by-line to familiarise themselves with the data and construct codes employing a constant comparative method. The code comparison and data synthesis then took place during which phrases and key words were highlighted to identify the emerging categories. Next, the codes were categorised into meaningful groups and analogous categories based on contextual concepts reaching theoretical saturation and generating themes and subthemes. Subsequently, the researchers returned to the original transcripts, repeatedly reviewing the codes and looking for consistency and coherence among the extracted codes, ensuring that the emerging concepts resonated with the participants' views and ideas. Finally, themes and subthemes were defined and classified. Nvivo 11 aided the process for organising the data.

In qualitative studies, trustworthiness or rigour determine the degree of confidence in data, ensuring the quality of a study. Lincoln and Guba's criterion was used to ensure trustworthiness that comprises credibility, dependability, confirmability, transferability, and authenticity.²² Credibility or confidence is the truth of the study findings, achieved in the study with prolonged engagement with participants, persistent observation, and peer debriefing. Dependability is the stability of the data over time, suggesting the homogeneity of a phenomenon experienced by subjects in changing conditions, achieved in the study through peer debriefing and maintaining an audit trail of process logs. Confirmability is the consistency of the findings that make a study reproducible, which was ensured by peer debriefing and maintaining an audit trail of analysis. Transferability is the extent to which research findings are effective in another setting, which was achieved by providing the details of the participants' characteristics and supportive quotations.

Results

Of the 21 subjects, 13(62%) were males and 8(38%) were females. The overall mean age was 32.24±7.58 years (range: 18-50 years). In terms of relationship with the patient, 9(43%) were fathers and 6(28.6%) were mothers. Majority of participants had completed secondary education, with the highest degree being a Master's in Economics (Table 2). Each FGD had 7(33.3%) subjects.

A total of 8 categories emerged, depicting family perception and experience of the FCC in the tertiary-care

Table-2: Socio-demographic characteristic of the participants (n=21).

Characteristics	n (%)
Mean Age (years)	32.24±7.58
Max. 50 years	
Min. 18 Years	
Gender	
Male	13 (61.9)
Female	8 (38.1)
Relationship with patient	
Father	9 (42.9)
Mother	6 (28.6)
Uncle/Aunt	5 (23.8)
Grandparent	1 (4.8)
Marital Status	
Married	21 (100)
Un-married	0 (0)
Education status	
Uneducated	6 (28.6)
Educated	15 (71.4)
Education completed	
Primary (1-8)	2 (9.5)
Secondary (9-10)	3 (14.3)
Intermediate (11-12)	3 (14.3)
Graduation	7 (33.3)
Ethnicity	
Sindhi	10 (47.6)
Punjabi	4 (19.0)
Urdu	3 (14.3)
Baloch	2 (9.5)
Pathan	1 (4.8)
Siraiki	1 (4.8)
Former Experience of Hospitalization	
Yes	15 (71.4)
No	6 (28.6)
Child admitted in which Paediatric ward	
Medicine Ward	5 (23.8)
Surgery ward	4 (19.0)
Endocrine Ward	5 (23.8)
Nephrology Ward	2 (9.5)
Paediatric Intensive care unit	5 (23.8)

public-sector hospital (Table 3).

The first category was parents' notions about their roles in parenting. Parents said they loved their children and considered them a divine gift, adoring them with love and care. Parents admitted the sensitivity and susceptibility in the case of their children. The illness in children was agonising for the family, but the parents upheld their responsibility to confront hardships passionately. They affirmed that they did not care about public opinion, especially if a child had any medical condition, like genital ambiguity, which is considered a taboo in society, not influencing their parenting roles. The participants upheld the idea that parenting was a 50-50 responsibility, and asserted that mother and father were equally vital for children, and the existence of both was indispensable.

"I got upset and sorrowful, but ... he is our child, and for children, one has to bear a lot." (Participant 2)

"When you stop caring about people, then you can nurture your children better." (Participant 3)

"Both the mother and father are equally vital for a child. Without a mother, the child's life is not good, and without a father, the child's life is nothing." (Participant 5)

The second category was acknowledging the strength and shortcomings of hospital admission. The participants described the hospital experience as the most agonising period and stage of physical, mental and emotional stress. They raised the concern of being scared by the hospital environment and getting upset upon encountering overcrowded wards. Their distress aggravated when they were not allowed to stay with their children. Having no place to rest and passing sleepless nights, parents also got sick. Notably, mothers suffered the most, as the paediatric wards were female-only wards, and mothers had to attend to the child alone, finding it difficult to manage the matters single-handedly. During this period of uncertainty, the parents needed someone to alleviate their distress.

"We are also humans, and we also want rest." (Participant 5)

"I did not eat for two consecutive days ... Now I have my child on a ventilator; how can I leave him?" (Participant 15)

"A mother is always sitting on a chair, so the parents also fall sick." (Participant 2)

The third category was disregarding the importance of a father. In Pakistani culture, the authoritative head of the family and the most relevant person is the father, on whom the decision-making relies. In paediatric hospitals, only female attendants stay with the patient, and fathers are allowed to come merely as visitors during visiting hours. In addition, the information-sharing with the father is not up to mark and the doctor counsel the mother, neglecting the father. As a result, fathers felt sidelined, resulting in desperation in the father and distress for the family, especially in cases when the child was emotionally attached to their fathers, and mothers found it difficult to console them. Therefore, parents demanded administrative reforms permitting fathers to meet and spend time with the child, attend the rounds, and to get involved in patient care and decision-making.

"The father is the main decision-making person." (Participant 4)

"More than half of the illness in the child goes away just after seeing a father." (Participant 9)

Table-3: Categories and codes related to the perspectives of the participants regarding family-centred care (FCC).

<p>Parent notions about their roles in parenting: Children are a blessing and dear to the parent: Parents cannot see their children suffer: Bearing hardships for their children A Child needs both the mother and the father Public opinions do not matter Equally significant roles of both the father and a mother</p>	<p>Emotional and Religious Narrative Mentally and emotionally upset Entirely prostrated and heartbroken A feeling of being humiliated Becoming short-tempered owing to anxiety, stress, fear, and lack of sleep Worries and sorrows Feeling of helplessness Expressing faith in Allah and not losing hope</p> <p>Social issues Inadequate facilities in the periphery Lack of acquaintance and accommodation. Extreme poverty and unaffordability Illiteracy, unawareness, and language barrier</p>
<p>Acknowledging the strengths and shortcomings of hospital admission: The most stressful period Scared upon arrival at the hospital The wards are overcrowded with patients No place to take a rest Parents getting sickish</p> <p>Disregarding the importance of a father Father- the most concerned and decision-making person A feeling of being sidelined Inadequate information sharing</p> <p>Experience and Current status of FCC Unnecessary restrictions on family visitation Being neglected and ignored Not involved in care as team members Lack of guidance and information sharing Unsatisfied by the provision of FCC The disrespectful attitude of the hospital staff The positive feedback</p>	<p>A mother's concerns The mother only wants her child well Mothers lacking confidence Mothers are not weak or little-hearted Mothers need rest</p> <p>Expectations and preferences for FCC Need someone to listen and console Need someone to guide and counsel Allowing both parents to stay with a sick child A father-child meeting area Involving parents in the care of sick children Involving parents at the time of procedures Teaching sessions for the parents Ethical training for nurses Avoid abrupt breaking of bad news. Appropriate waiting area for the family Leniency in the hospital visitation policy</p>

"They do not allow me to enter, and I cannot even see my child." (Participant 9)

"Whenever the round occurs, the fact is that they do not allow us to get inside." (Participant 10)

The fourth category was mothers' concerns. The mothers professed that they lacked the confidence to deal with matters, needing the assistance of their male counterparts. They stressed that that they only wanted their children well regardless of the circumstances. But at the same time, they endorsed that they were not weak of heart or mind. They described their hospital experience as exhausting and appealed to make the system convenient for giving them rest by allowing fathers to share responsibility during hospital admission.

"When a child becomes unconscious, then how much does it hurt a mother? The father is just like ... arranging a car, doing this, and doing that ... but the mother; the mother only wants her child at that time." (Participant 14)

"I am not weak-hearted, and neither had I believed in it." (Participant 14)

"Surely, when the mother will have rest, only then she could be able to look after their children." (Participant 2)

The fifth category was emotional and religious narrative. The participants established an emotional narrative of being mentally upset during the hospital stay, considering it the most agonizing moment, and making them feel exhausted. The parents revealed that during this period, they felt overwhelmed by apprehension, uncertainty and anxiety, and, being negligent about their health, comfort and sleep, made them short-tempered.

"The child is hanging between life and death. What affliction the mother and the father are going through, no one knows." (Participant 5)

"A person is shattered entirely. A person is anxious if something happens to someone in the home, especially to young children. Then what you can think will be the situation for the mother, father, and the whole family?" (Participant 15)

In this period of despair, the parents were looking for respect, empathy and welcoming gestures from the hospital staff, but maltreatment left them disheartened and demoralised, producing a feeling of helplessness and despondence due to apathetic attitude encountered during the hospital stay, aggravating their disappointment. The parents revealed that sometimes they would just burst into tears, being overcome by the perplexity of the circumstances and troubles their families had been facing.

"It hurts a lot; we are humans ... we get distressed, we feel sorrow, we can do nothing." (Participant 20)

"Certainly, we will also misbehave with them in reaction." (Participant 6)

"Our child is very sick. I can only cry when I see the child. To whom should I talk? To whom should I say?" (Participant 19)

"They all have come in real need and are not here by choice ... We come here compelled by dire need, but no one listens to us." (Participant 9)

Besides, the participants expressed faith in Almighty, preventing them from losing hope and making them optimistic about a tremendous tomorrow.

"We say that by Allah's will, all things will get well." (Participant 18)

"We are thankful to God for each and everything ... Whenever we are thankful, things go on getting resolved on their own." (Participant 14)

The sixth category was social issues. Often, due to lack of facilities in their hometowns, people arrived for treatment from distant areas along with their whole families, and were then compelled to live under the open sky, lacking acquaintance and accommodation in the locality. This population was generally an uneducated, impoverished, and largely unable to even afford to purchase milk for their children. In addition, they had difficulty fulfilling administrative requirements due to illiteracy and language barrier.

"People coming from elsewhere have no know-how here. There is no relative. They have to stay here 24 hours a day and are unaware of things as well." (Participant 9)

"When we came here, we borrowed money from others, and then came here; we did not have money at all." (Participant 1)

"The domestic expenses are high. We have two children, and one is sick. I have been coming here for the past six months. So, we are left with less cash, which means no money left." (Participant 6)

"We do not have the ambulance fare to pay ... How can we go to a private hospital?" (Participant 12)

"A mother cried because she could not afford a thermometer worth just a hundred rupees." (Participant 5)

The seventh category was experience and current status of FCC. Owing to unwanted restrictions, the participants perceived the hospital visiting policy as a source of exaggerated distress for the patient and the family. They stressed that guidance to families was inadequate and that information-sharing was unsatisfactory. They felt sidelined and did not consider themselves part of the team, and the main reason was not being allowed to accompany the patient, especially during the ward rounds. They reported feeling hurt by the disrespectful attitude of the staff and related it with staff shortage, but still felt offended and were resentful.

"My son was in the emergency room, and neither did they let my husband go nor I ... I was crying as he was in trouble, but they were not letting me go ... My son was alone all night." (Participant 6)

"I have my child on a ventilator; how can I leave him and go downstairs? There must be a little leniency." (Participant 15)

"They are not allowing us to see the patient ... At least we should be allowed to pay a single visit to a patient." (Participant 8)

"My son was in great pain, but everyone was scolding me; the doctor was scolding, the nurse, and everybody was saying: 'Just go and sit, or otherwise go home...' They did not have respect at all." (Participant 13)

"They treat us like someone treats a dog; Get out! Get out! That is not the way." (Participant 20)

Upon asking the participants to score the current status of the FCC they observed during the admission of their children, the collective stance was that they had not experienced FCC in any way, and collectively scored it 0. They acknowledged that constrained resources limit FCC provision and regarded it as a care model suitable only for developed countries.

"It is zero." (Participant 8)

"Till now, we have seen nothing about the family." (Participant 10)

"Things are all right in view of the limited resources." (Participant 14)

The eighth and final category was expectations of and preferences for FCC. The participants acknowledged that they had no complaints as far as patient care and treatment was concerned. They appreciated the efforts of the doctors and the staff and considered them friendly, well-disciplined and caring for the patient.

"They laugh with children, they play with them, and they make the children laugh and be cheerful." (Participant 12)

"The doctors are very caring, they are careful in every way, and they are disciplined ... What I liked the most about this hospital, is the way of treatment here. Because I never thought that there is so much good treatment in a government hospital or that the doctors take so much care of the patients. I am completely satisfied here." (Participant 15)

Paediatric hospitals only allow female attendants, and father comes just as a visitor. This aspect was distressing for most fathers, who demanded a meeting area to spend time with their sick children. Separating children from their parents eventually resulted in restlessness in both parties. The participants appealed for permission to stay with their children during hospitalisation and wished to be included in the caring of their sick children, especially during any procedure, as their presence would calm the child and enhance the parents' satisfaction.

"A child cannot understand that if it is a female or male ward."

There should be at least a room so that a male attendant may come and sit with his child." (Participant 5)

"Father and mother should be together with the child, whatsoever the situation, because they will encourage each other." (Participant 13)

"When you pass an NG [nasogastric] tube, the child is scared, and the mother should remain close to him." (Participant 5)

"If there is no person around, how will the child stay? And how will the child allow any procedure?" (Participant 13)

The participants exhibited anxiousness and unawareness of the rules, making them prone to blunders. They said they needed someone to listen to them patiently and guide them appropriately. They asserted the need to arrange teaching sessions for the family attending the children, and educating them about their rights and responsibilities. The parents also suggested educating the staff about ethics so that they could deal with family members professionally.

"Doctors should explain to parents the particular problems of the child." (Participant 13)

"You can also say something in a better way ... Because people who come here are already suffering and come here helpless." (Participant 15)

"A basic training session for parents is also needed ... a lecture or a class." (Participant 4)

The participants were of the view that whenever anything unexpected happened to any loved one, especially the children, it is a crucial time for the family members, as they needed to settle their nerves. They urged the doctors to avoid breaking news abruptly and matter-of-factly, and to avoid stating that the child was critical because the parent may lose their whatever strength they may have or lose all hope.

"If they say everything straightforwardly, then a person may get into a shock." (Participant 11)

People visiting the hospital were arriving from distant areas, and sometimes they had to stay for weeks, so the participants stressed the importance of an appropriate waiting room for the family where they could rest.

"There is no place at all to sit ... there should be a waiting area, and at least there should be some space to sit outside." (Participant 2)

Lastly, the participants demanded a family-friendly visitation policy, allowing the family to visit the patient without restraints, and allowing the father to stay with the child if he so preferred. The participants were hopeful of an

environment where parents and family could play their role in patient care as team members, and were given respect and treated politely.

Discussion

The current study is the first of its kind, reflecting the Pakistani context of the parental and family views on FCC. In Pakistan, the population visiting a public hospital constitutes the illiterate and low-income class, rearing a number of children within limited resources. Due to limited access to healthcare, people are obliged to travel to major cities for treatment, leaving their livelihood and sometimes coming with whole families in a situation where they are without shelter and fundamental necessities.

The status of FCC in Pakistan is unsatisfactory as the visitation policies in paediatric hospitals are strict, and attendants are not allowed to stay with the patient in ICUs, while only a single female attendant can stay in the general wards, and the rest of family members, including the father, can only visit during the designated visiting hours. The results are restlessness and agitation in the family, especially among fathers, who become desperate to see the child and know about his wellbeing. In the wake of the coronavirus disease-2019 (COVID-19) pandemic, the restrictions were made stricter than ever, adversely affecting the FCC, damaging a family's physical, psychological and emotional health, and increasing the rate of post-intensive care syndrome.

Parents and family members perceived FCC as unlimited parental access to stay with and look after the patient, and to be involved in the rounds, procedures and decision-making processes. The family wanted healthcare personnel to listen to them patiently, deal with them with respect, guide them appropriately, and educate the parents. Parents wished to get involved in patient care and meet sick children without restriction. They demanded a place in the wards where a father could spend time with his sick child, and an appropriate waiting area for the rest of the family. They urged the healthcare providers to educate the parents, especially mothers, providing them with emotional support and taking timely feedback. The family demanded a lenient hospital visiting policy where family members would decide to what extent they wanted to be involved in patient care and decision-making.

The participants in the study expressed concerns regarding the family-restrictive hospital visiting policy and the deplorable in-hospital experience of FCC. The parents and family members felt marginalised and distressed due to restrictions in the way of accompanying the patient, especially during procedures and ward rounds. The participants reported inadequate guidance, unsatisfactory

Table-4: Key recommendations.*

Family-Friendly visitation policy	To establish a well-regulated parent and family-friendly visitation policy, allowing families to visit patients without unnecessary restrictions while maintaining order and discipline across the wards.
Family-Conducive waiting areas	To construct appropriate waiting areas for families, considering their needs for rest and comfort during the hospital stay, and structuring them to provide adequate space and amenities to contribute to a more conducive and family-friendly environment.
Accommodation and support for families arriving from distant areas	Recognizing the challenges faced by families traveling from distant areas and providing them appropriate accommodation, addressing the language barriers, providing emotional support, and facilitating them to deal with social challenges.
Providing Emotional support	To acknowledge the mental and emotional distress experienced by parents and families during their child's illness and hospital stay, providing them emotional support, and addressing their issues and concerns in an empathic and respectful manner to alleviate their feelings of despair and helplessness.
Improved communication and information sharing	To Enhance communication between families and healthcare providers and share the child's condition and treatment plans comprehensively with families on a day-to-day basis. Organize concise teaching sessions and pamphlets/flyers for parents and families about their rights and how to comply with hospital rules and regulations.
Hospital Complaint management system	Listening to the complaints of parents and families and addressing them in the best possible way, especially addressing the disrespectful attitudes and maltreatment reported by parents. Creating an environment for an open dialogue between healthcare providers and families and addressing any doubts and misconceptions parents or families may have.
Inclusion of fathers in patient care and decision making	To Assign designated areas or rooms for fathers to allow them to spend time with and involve them in the care and decision-making of their sick children.
Facilitating and empowering mothers	To provide assistance and emotional support to mothers who may lack confidence or feel exhausted or overwhelmed and to educate and empower them to the greatest extent.
Interacting with parents and families during ward rounds	Involving parents in routine patient care and encouraging them to participate in daily ward rounds, listening to families and addressing their concerns compassionately, gathering their feedback and emphasizing shared decision-making, and communicating with families courteously and in an understandable way.
Sensitivity in Delivering an unpleasant or sad news	To Deliver a piece of news about a child's condition with sensitivity and compassion, considering the aptitude and emotional state of parents and families.
Education about communication skills and ethical training of hospital staff	Conduct ethical training sessions for hospital staff, including nursing attendants and guards, about how to deal with families with compassion and respect while maintaining patient and family dignity and teaching them basic communication skills on how to counsel the parents or deal with hot-tempered families or manage a rampaging situation.
Creating a patient-centred and family-friendly environment both inside and outside the wards	To recognize the importance of family cohesion and its positive impact on the child and the family's well-being, and maintaining a welcoming hospital environment to alleviate

*Recommendations are formulated based on focus group discussions (FGDs) with the parents and family members of children admitted to the National Institute of Child Health, Karachi.

information-sharing, and disrespectful attitudes, which they attributed to insufficient staff strength. They shared instances when not being able to stay with their children, especially in critical situations, caused them emotional distress. When asked to score the current status of the FCC, the participants collectively rated it 0, relating inappropriately delivered FCC to resource constraints and perceiving it as a care model more suitable for developed countries. Despite these limitations, the participants acknowledged the doctors' efforts, describing them as caring and well-disciplined. They expressed the desire that fathers should have a meeting area in the wards and to be included in their children's care, particularly during procedures, to provide child comfort and enhance family satisfaction. The participants emphasised the need for someone to console and guide them, appealing for teaching sessions to educate families about their rights and responsibilities. They also highlighted the importance of doctors breaking bad news tactfully, showing empathy and avoiding abrupt or overly critical statements that could

undermine the family's emotional wellbeing. The participants stressed the need for a suitable waiting area for families, considering the often lengthy stay at the hospital. Lastly, they advocated for a family-friendly visitation policy, unrestricted by needless limitations, urging an environment where parents and families were treated respectfully and viewed as integral care team members. Based on FGDs, a set of recommendations was generated to enhance FCC in paediatric public hospitals that are low-cost and easily applicable in developing countries, like Pakistan (Table 4).

The current findings were comparable to those of studies that identified FCC dimensions, like family involvement and empowerment, education and information-sharing, building consensus and shared decision-making, relieving pain and anxiety, respect for patient values, cleanliness and privacy, and emotional support and coordination.²³⁻²⁵

In developing countries, FCC implementation seems to be challenging, as it demands organisational commitment

and the healthcare provider's understanding.

An absence of a hospital FCC policy, a stubborn visiting schedule, limited resources, and the incompetence of healthcare providers with respect to interaction with families impede the implementation of FCC, which needs amendments to ensure institutional flexibility and healthcare professional training in communication skills, like respect and tolerance, to meet the psychological needs of the families.

In addition, evidence suggests that in a situation indicating patient isolation, as in a pandemic, FCC can still be continued without interruption via nonphysical ways through strategies, like video conferencing and online counselling, to achieve FCC goals.

The current study has limitations as it relied on self-reported data which may have had recall bias. Since the study was conducted at a single public-sector hospital, the findings may not be generalisable.

Conclusion

Several significant categories were identified regarding FCC experienced by parents and families and their perceptions and preferences. There was an acute need for improvement in FCC delivery.

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Author Contribution:

UT: Study concept, analysis, interpretation of the study findings, designing the methodology. Moderator during the focus group interviews, audio recording, transcription, and translation, maintaining the audit trail and documenting the verbal and nonverbal cues during communication. Interpretation of the study findings, preparing and approving the final draft.

MA: Validating the study idea, analysis and interpretation of the study findings, final proofreading.

ZAK, SHA: Analysis and interpretation of the study findings, proofreading.

NN: Analysis and interpretation of the study findings, audio recording, transcription, translation, final approval.

MJ: Analysis and interpretation of the study findings, assistant moderator during the focus group interviews, contributed to the audio recording of the session, maintaining the audit trail, documenting the verbal and nonverbal cues during communication.