DOI: https://doi.org/10.53350/pjmhs2115112882

ORIGINAL ARTICLE

Evaluation of patient and Family-Centered Care; a Survey of Neonatal and Paediatric Intensive Care Units at a Tertiary Care Hospital in Lahore, Pakistan

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ABSTRACT

Aim: To evaluate the application of the principles of Patient and Family-centered Care
Methodology: A cross-sectional study was conducted in the Pediatric and Neonatal Intensive care unit of a tertiary care hospital in Punjab, Pakistan. IRB approval was granted, and the study spanned a period from January 2019 to June 2019. A questionnaire was created to survey the pediatric patient's parents. Data analysis was done using SPSS 25.
Results: A total of 158 responses were recorded. The majority of the parents felt that patient and family-centered care was not being applied to the admitted patients' management plans in the pediatric and neonatal ICUs.
Conclusion: The treatment of patients in the pediatric and neonatal ICUs was not following the principles of patient and family-centered care. Therefore, further studies are required to improve the ease of access, alongside limiting the barriers to the patient and family-centered care in Pakistan. This way, patients can benefit from improved outcomes associated with PFCC.
Keywords: Neonatal intensive care unit (NICU), intensive care unit (ICU), pediatric intensive care unit (PICU), patient and family-centered care (PFCC).

INTRODUCTION

Patient Family-Centered Care (PFCC) is the core component of quality health care that prioritizes patients' preferences, needs, and values. It also allows an exchange of ideas, belief systems between patients, their families, and health care providers[1].

In 1969, Enid Balint conceptualized PFCC as a contrast between patient-centered medicine and illness-centered medicine. It was primarily introduced to help patients understand information better and improve communication between the providers and families. The importance of PFCC is highlighted in an ICU, where an overload of information is present. The complex nature of the provided care often requires increased engagement between providers and patients. In such an environment, patient and family-centered care can help patients' families better comprehend information regarding their management.

PFCC is an approach that integrates an understanding of disease and illness with the individual's experience within the healthcare system. It reinforces the need to develop a mutual relationship based on care and understanding between healthcare providers and their families. Hence, in many developed countries, PFCC has been incorporated because it proved to be beneficial for the planning and delivery of healthcare[2,3].

It has been advocated for by the Institute of Medicine (IOM), the American College of Critical Care Medicine (ACCM), and the American Academy of Pediatrics (AAP).

In 2001, IOM reported the effectiveness of PFCC in influencing clinical decision making and, as a result, affecting the outcomes in the ICU. Furthermore, the Institute of Healthcare Improvement (IHI 2013) suggested that PFCC can help raise patient satisfaction scores to improve results. It also reduces costs by changing hospital or practitioner practices. Furthermore, PFCC can encourage engagement or accommodate individual and family members' needs and preferences[4].

The principles of PFCC have a spectrum of focus. When talking about "respect and dignity," physicians must actively involve patients and family members in decision-making. While "information sharing" patients should be conducted thoroughly, using terms and language that the patients comprehend. The patient must play an active role when corresponding with the physician regarding their health and treatment strategies, highlighting the underlying principle of "participation." A "collaborative" effort can ensure that patients, families, health care providers, leaders can all work together.

Work can be done not just on the delivery of care but also on policy matters, program development, and the implementation of ideas and research[5].

It is pertinent to acknowledge that PFCC is not commonly used within the national healthcare system. The wide-scale lack of implementation of PFCC in the country means that physicians often only focus on treating the patient's illness and fail to spend apt time trying to understand the difficulties faced by the patient. In addition, the families may also be disregarded. There are organizational barriers, time constraints, conflict with other doctors, lack of support from nurses, family visitation policies of individual hospitals, and communication barriers with patients, leading to difficulty applying PFCC[6]. Another challenge is our population's literacy rate and lack of schooling, which ultimately acts as a roadblock to communication between providers and patients. PFCC is an approach that requires effective communication of knowledge from the provider to the patient and their families. Effective communication may not be possible with our population's lack of understanding of primary and common medical jargon.

This study aims to understand to what extent patient and family-centered care are implemented in Pediatric and Neonatal ICU at a tertiary care hospital in Lahore. Through this study, we can locate the aspects within Pakistan's healthcare system that are deficient regarding PFCC. Another goal is to recognize how it can be implemented to achieve greater patient satisfaction and outcomes. Ultimately, this may help bring a model of patient and family-centered care into practice in Pakistan.

METHODOLOGY

This cross-sectional study was conducted from January 2019 to June 2019 at the Pediatric and Neonatal Intensive Care Units of a tertiary-care hospital in Punjab, Pakistan. It was initiated after obtaining permission from the Institutional Review Board with the

Received on 17-05-2021
Accepted on 29-10-2021

condition that the hospital's name is kept confidential for publication. The hospital has agreed to participate in the study to improve general patient welfare and does not want to encounter negative marketing issues as it is a private setup. Informed written consent was taken from the participants. A questionnaire was filled by the parents of the patients admitted to the Pediatric and Neonatal Intensive Care Unit. Our questionnaire was based on the six principles of PFCC as outlined by the AAP, which is

1. Listening to and respecting each child and their family
2. Ensuring flexibility in organizational policies, procedures, and practices
3. Sharing complete, honest, and unbiased information with patients and families
4. Providing and ensuring formal and informal support for the child and family
5. Collaborating with patients and families at all levels of health care
6. Recognizing and building on the strengths of individual children and families.

All demographic (including gender, age, occupation, and education) and relevant data were collected through the questionnaire. The participants included in the study were aged 18 years and above, both male and female. They had a child in either the Paediatric or Neonatal Intensive Care Unit. Second members of the same family were excluded. Through a random sampling method, 191 parents were approached to fill the questionnaire, and 158 were recorded. Statistical analysis was performed using SPSS 25. Categorical data were summarised as percentages and frequency. A p-value of less than 0.05 was considered statistically significant. Analysis of patient attendant responses was done to understand whether core concepts of PFCC were being implemented in the paediatric and neonatal ICU. In addition, deficiencies that remained in the application of PFCC were also assessed.

RESULTS

The study included parents of 158 patients admitted to the hospital's Neonatal and Paediatric Intensive Care Units. The age group of the patients can be *seen in* Table 1**.** The study included more males than females. Among them, the majority were new-borns and infants. The rest consisted of toddlers, pre-schoolers, school-aged children, and adolescents. Moreover, out of the 158 patients, 68(43%) were admitted to the Neonatal Intensive Care Unit, and 90(57%) were in the Paediatric Intensive Care Unit. The responses of the patient's parents to the questionnaire can be seen in Table 2.

Table 1: Age group of the patients admitted in the ICU

Age Group	Frequency	Percentage
New-born	70	44.3
Infant	40	25.3
Toddler	16	10.1
Pre School	8	5.1
School Aged Child	22	13.9
Adolescent	2	1.3
Total	158	100.0

Table 2: Responses of the patient's Parents to the assessment of Patient and Family-Centered Care (PFCC) in Neonatal and Paediatric Intensive Care Units

Type of ICU	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The hospital staff and doctors respect your child and family					
NICU	6 (25.0%)	0 (0.0%)	4 (66.7%)	38 (48.7%)	20 (58.8%)
PICU	18 (75.0%)	16 (100.0%)	2 (33.3%)	40 (51.3%)	14 (41.2%)
Organizational policies, procedures, and practices were flexible and family-centric					
NICU	4 (25.0%)	6 (16.7%)	6 (37.5%)	38 (52.8%)	14 (77.8%)
PICU	12 (75.0%)	30 (83.3%)	10 (62.5%)	34 (47.2%)	4 (22.2%)
Doctors here share complete, honest and unbiased information with you					
NICU	8 (26.7%)	0 (0.0%)	6 (42.9%)	30 (48.4%)	24 (66.7%)
PICU	22 (73.3%)	14 (100.0%)	8 (57.1%)	32 (51.6%)	12 (33.3%)
You have access to formal and informal support for your child					
NICU	8 (44.4%)	4 (15.4%)	12 (54.5%)	28 (41.2%)	16 (66.7%)
PICU	10 (55.6%)	22 (84.6%)	10 (45.5%)	40 (58.8%)	8 (33.3%)
Hospital staff meets the level of health care for you and your child					
NICU	4 (20.0%)	6 (30.0%)	6 (42.9%)	28 (41.2%)	22 (64.7%)
PICU	16 (80.0%)	14 (70.0%)	8 (57.1%)	40 (58.8%)	12 (35.3%)
Hospital is helping in building strength of every individual					
NICU	4 (22.2%)	8 (40.0%)	14 (31.8%)	24 (44.4%)	18 (81.8%)
PICU	14 (77.8%)	12 (60.0%)	30 (68.2%)	30 (55.6%)	4 (18.2%)
Family visitation hours are satisfactory					
NICU	8 (44.4%)	4 (13.3%)	6 (27.3%)	32 (53.3%)	18 (64.3%)
PICU	10 (55.6%)	26 (86.7%)	16 (72.7%)	28 (46.7%)	10 (35.7%)

DISCUSSION

Patient and Family-Centered Care is a model that aims to build a relationship of mutual trust, respect, and understanding between the patients, their families, and healthcare organizations. The study was conducted to evaluate the extent of PFCC application within the healthcare systems in Pakistan concerning core principles practice. One aspect covered was whether the hospital staff and doctors respect the child and family. Most parents either disagreed or strongly disagreed that the doctors and hospital staff treated the patients and families with respect in this category. Our data shows that the NICU group gave more unsatisfactory responses to this question compared to the PICU. The lack of satisfaction may be due to the NICU being an overall more stressful place for new mothers. This reflects a lack of application of the very basic core concepts of PFCC.

New mothers, the baby's need for respiratory support, and lower gestational age (pre-term babies) have been reported to be significant predictors of stress and negative feelings in parents[6]. Some studies showed that certain factors contributed more to paternal stress in the NICU, thus leading to more negative unsatisfactory responses[7]. These factors include sights and sounds of the NICU environment, perception of the mothers regarding baby's discomfort, lower birth weight of babies, and babies being on ventilators.

A study found that respect and dignity are interrelated. ICU patients are more prone to feeling disrespected because of the state of illness and circumstances they find themselves in. Violations of respect may be more common in the ICU as patients may undergo more "dehumanization," which is the loss of positive, human qualities. ICU patients can often suffer from this because they lack consciousness, agency, and free will, leading to patients and attendants feeling more helpless and sensitized to feeling disrespected. Studies suggest a need for more research to prevent lapses in respect and dignity in the ICU. Ultimately, more research

will help identify the root causes that have to be addressed and considered for greater accountability in the ICU[8].

When the patient and family were asked about how much access they had to formal and informal support, 58 % of the responses were a combination of disagreeing and highly disagreeing. Formal support is considered the paid support offered to patients and their families, such as neonatal social services and psychiatry, often arranged by the healthcare organizations[9].

Social workers take on strengthening families, promoting positive developmental outcomes through assessment, advocacy and support. They identify the communication breakdown between healthcare providers and families and resolve them. Social workers also help develop coping strategies against the general anxiety and stress of families[10].

Whereas informal support is the unpaid support that the patient's family and friends provide. There are many challenges posed to families in the ICU, such as feeling powerless and vulnerable. Family members often struggle to maintain their mental health and well-being. There is often distrust of the provider's approach, exhaustion, and mixed feelings when patients transition from the ICU to the general ward.

Intervention studies, based on quasi-experimental design, examined modified visiting hours, strategies to provide information, nurse-led transitional care programs, and educational support from the staff. Measures to improve informal support include increasing flexibility in family visitation hours, growing seating arrangements for close family and friends outside the ICU, increasing educational support from the staff, and information provision strategies. However, it could be due to current hospital COVID restrictions to limit the risk of infection spread, especially to vulnerable healthcare providers and families.

Three sources of informal support were identified in a recent study conducted: (1) emotional support, referring to the provision of care, warmth, and understanding; (2) instrumental support, referring to practical assistance for daily activities; and (3) informational support, e.g., provision of knowledge and advice[11].

The data highlights a lack of formal and informal support to patients and their families in the NICU. It can stem from the absence of provision of neonatal social services by healthcare providers and inflexible hospital visitation hours, which coincide with office hours for people. Some patients travel from farther areas and thus, have no relatives and friends. Such factors negatively impact patients and the family because it enhances an isolated feeling in times of stress and anxiety.

On being asked to rate how thoroughly and honestly the healthcare professional did relay information about the patient's diagnosis, most responses recorded showed dissatisfaction. Information sharing is one of the essential principles of PFCC. It highlights that the information shared by the doctor with the patient and family should be accurate and level-appropriate. [12] The process of information sharing is purely factual and does not involve discussing strategies and decision-making. The primary purpose of information sharing is to create a mutual relationship between patients, families, and healthcare providers to ensure quality care[12].

The manner of sharing must be complete, honest, and unbiased. Because of cultural and linguistic variation, the language and terms used should be more straightforward for the patients and families to understand. This eventually allows them to participate equally when it comes to making decisions. The method of information sharing can also be improved when the healthcare providers engage with the patients and their families during hospital rounds when the nursing staff is also present because it highlights the need for the family's involvement when it comes to patient care[13].

Healthcare providers should also always focus on building on the strengths of every individual, including the patient and family members. However, the study results mark an absence of strength building, probably because illness and hospital stays generate stress and anxiety with no outlet. A negative patient experience and leads to communication breakdown between provider and patient.

It is essential to identify sources of family strengths, which help recognize positive aspects of a family system and encourage them[14,15]. Focusing on building family strength helps overcome feelings of vulnerability in the hospital environment. It is common to witness patients and families struggling with anxiety and depression in the hospital[16].

The majority of the participants disagreed that the hospital rules and regulations concerning ICU were flexible. Rigid hospital rules and regulations can be a source of additional stress as mothers cannot breastfeed or pump feed and have limited access to the baby. Studies have reported negative impact on families. Frustration among parents has been observed due to their inability to spend time with their children[17].

In addition, most of the participants were dissatisfied with the number of visitation hours. The restriction to visitation hours is due to several factors, such as discretion, confidentiality, and lack of space and staff to accommodate the parents. A study reported that open visitation hours helped reduce family anxiety and depression and improve patient outcome[18]. The current study results are per the studies available, highlighting the need for improved flexible visitation hours and hospital rules and regulations to facilitate the families in their time of need.

The majority of the parents felt that the core principles of PFCC were not enacted by healthcare service providers in the provision of treatment to their children. Since this survey was done, the contributing hospital has been committed to improve patient care by making numerous changes to improve its care and feedback. It is also anticipating a follow-up study in the next few years. Public and private hospitals need to internally evaluate to improve and survey the input according to PFCC standards. The PFCC health model positively impacts patient outcomes, such as reducing infant's duration of stay and readmission rates, improving weight gain, increasing breastfeeding rates, decreasing parental anxiety, and increasing satisfaction with the quality of care. High-quality patient-centeredness was associated with reduced non-urgent emergency department visits for the paediatric age group[19].

CONCLUSION

There is a clear need in Pakistan to create awareness among healthcare workers and medical students about the importance of PFCC. Literacy and education levels of our population create a barrier in patient-physician communication. However, contributing factors to the healthcare system include inadequate staffing, overcrowding of ICUs, the hospital social services department being non-existent in the country's private setups, and a lack of specialists in intensive care medicine. This study indicates that our patient population is not benefitting from an approach that could significantly improve patient care. More studies are required to address and curb barriers in Pakistan systematically. PFCC is a tool that can be effectively implemented to enhance the provision of services in healthcare settings.

Limitations: There were parameters not taken into consideration when the survey was conducted. The clinician's point of view regarding patients and families was not taken into account. Sample biases and patient literacy rates were also not taken into account. Furthermore, the sample size of the study used to conduct the survey was small.

Author contributions: WHZ:-Data analysis, manuscript writing, manuscript review, **MM:** Manuscript editing, review and final approval, **SAA:** Intellectual genesis and manuscript writing, **MRA:** Manuscript writing, **NH:** Manuscript writing, **MU:** Manuscript writing, **ANB:** Data manipulation and data cleaning/analysis

Conflict of interest: We confirm that none of the authors have any conflicts of interest or other relevant disclosures pertaining to this manuscript.

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