Patient and Family Centered Care: Practices in Pediatrics

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Abstract

Patient and Family Centered Care is an approach to planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. In pediatrics, Patient and Family Centered Care (PFCC) is based on the understanding that the family is the child's primary source of strength and support. Respect each child and his/her family, ensuring flexibility in organizational policies, procedures, and provider's practices, sharing complete, honest, and unbiased information with patients and their families, providing formal and informal support for the child and family, collaborating with patients and families at all levels of health care and recognizing and building on the strengths of individual children and families are the principles of PFCC. This approach is not only beneficial for patient and family but also for health care providers.

Keywords: *PFCC- Patient and family centered care, PCC-Patient centered care, FCC-Family centered care, NICU-Neonatal Intensive care unit, MCHB-Maternal and child health Bureau, FC-Family care, SC-Standard Care, FIC-Family Integrated care, CI- Confidence Interval, NIPI-UNDP-Norway India Partnership Initiative under United Nations Development, SNCU-Sick newborn care unit.*

Introduction

'Patient and Family Centered Care'(PFCC) is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.[1] When PFCC is practiced; it shapes health care policies, programs, facility design, evaluation of health care, and day-to-day interactions among patients, families, physicians, and other health care professionals. In pediatrics, patient- and family-centered care is based on the understanding that the family is the child's primary source of strength and support. The term 'family-centered care,' is replaced with the term 'patient and family centered care,' to more explicitly capture the importance of engaging the family and the patient in a developmentally supportive manner as essential members of the health care team.[2]

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Patient and Family Centered care in Past: PFFC emerged as an important concept in health care during the second half of the 20th century, at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and well-being of their children. Building on the work began in the previous decade; the Institute for Family-Centered Care (now the Institute for Patient- and Family-Centered Care) was also founded in 1992 to foster the development of partnerships among patients, families, and health care professionals and to provide leadership for advancing the practice of family-centered care in all settings.[3]

The First Hospital to care exclusively for children was the L'Hospital Des Enfants-Malades in Paris in 1802[4] and in the United States, the children's Hospital of Philadelphia in 1855.[2] In 1989 the Maternal and Child Health Bureau (MCHB) changed its mission to read: Provide and promote family centered, community-based, coordinated care for children with special health care needs and to facilitate the development of community–based systems of services for such children and their families.[5]

In 2001, the Institute of Medicine named Patient Centered Care (PCC) as crucial for health care quality and by 2003; the American Academy of Pediatrics had incorporated FCC into multiple policy statements and affirmed Family Centered Care (FCC) as the standard of health care for all children.[6]

Ortenstrand A etal. conducted a study to evaluate the effect of a new model of family care (FC) in a level 2 NICU, where parents could stay 24 hours/day from admission to discharge. A randomized, controlled trial was conducted in 2 NICUs (both level 2), including a standard care (SC) ward and an FC ward, where parents could stay from infant admission to discharge. In total, 366 infants born before 37weeks of gestation were randomly assigned to FC or SC on admission. The primary outcome was total length of hospital stay, and the secondary outcome was short-term infant morbidity. The analyses were adjusted for maternal ethnic background, gestational age, and hospital site. Total length of hospital stay was reduced by 5.3 days: from a mean of 32.8 days (95% confidence interval [CI]: 29.6-35.9) in SC to 27.4 days (95% CI: 23.2-31.7) in FC (P = .05). This difference was mainly related to the period of intensive care. No statistical differences were observed in infant morbidity, except for a reduced risk of moderate-to-severe bronchopulmonary dysplasia: 1.6% in the FC group compared with 6.0% in the SC group (adjusted odds ratio: 0.18 [95% CI: 0.04-0.8].[7]

Marion Mitchell etal, conducted a study to evaluate the effects on family-centered care of having critical care nurses partner with patients' families to provide fundamental care to patients. Total of 174 family members participated; 75 in control and 99 in intervention group. At the control site, patients' families experienced usual care; at the intervention site, patients' families were invited to assist with some of their relative's fundamental care with nurse's support. This study concludes that partnering with patient's family members to provide fundamental care to the patients significantly improved the respect, collaboration and support.[8]

Karel O'Brienetal. conducted a pilot prospective cohort analytic study to explore the feasibility, safety, and potential outcomes of implementing this model in a Canadian NICU. Families were provided with daily education sessions and were mentored at the bedside by nurses. The primary outcome was weight gain, as measured by change in z-score for weight 21 days after enrolment. For each enrolled infant, we identified two matched controls from the previous year's clinical database. They analyzed the differences in weight gain between the two groups by using a linear mixed effects multi variable regression model. They also measured parental stress levels using the Parental Stress Survey: NICU, and interviewed parents and nurses regarding their experiences with FIC (Family Integrated Care). They included 42 mothers and their infants in their study. They enrolled the infants for the study among which 31 completed the study. Researcher concluded that there was a significant increase in the incidence of breastfeeding at discharge (82.1 vs. 45.5%, $p < 0.05$). The mean Parental Stress Survey: NICU score for FIC mothers was 3.06 ± 0.12 at enrolment, which decreased significantly to 2.30 ± 0.13 at discharge ($p < 0.05$). This study suggests that the FIC model is feasible and safe in a Canadian healthcare setting.[9]

Components of Family-Centered Care practice include:

- Working with the family unit to ensure the safety and well-being of all family members.
- Strengthening the capacity of families to function effectively by focusing on solutions
- Engaging, empowering, and partnering with families throughout the decision and goal making processes.
- Developing a relationship between parents and service providers characterized by mutual trust, respect, honesty, and open communication
- Providing individualized, culturally responsive, flexible, and relevant services for each family
- Linking families with collaborative, comprehensive, culturally relevant, community-based networks of supports and services.[10]

Core concepts of Patient and Family Centered Care[11]:

1. Listening to and respecting each child and his or her family. Honoring racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporating them in accordance with patient and family preference into the planning and delivery of health care.
2. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values

of each child and family and facilitating choice for the child and family about approaches to care.

3. Sharing complete, honest, and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming, so that they may effectively participate in care and decision-making to the level they choose. Health information for children and families should be available in the range of cultural and linguistic diversity in the community and take into account health literacy. In hospitals, conducting physician rounds in the patients' rooms with nursing staff and family present can enhance the exchange of information and encourage the involvement of the family in decision-making.
4. Providing and/or ensuring formal and informal support (eg, peer-to-peer support) for the child and family during each phase of the child's life. Such support is provided so that Health Insurance Portability and Accountability Act and other relevant ethical and legal guidelines are followed.
5. Collaborating with patients and families at all levels of health care: in the delivery of care to the individual child; in professional education, policy making, program development, implementation, and evaluation; and in health care facility design. As part of this collaboration, patients and families can serve as members of child or family advisory councils, committees, and task forces dealing, for example, with operational issues in health care facilities; as collaborators in improving patient safety; as participants in quality-improvement initiatives; and as leaders or coleaders of peer-support programs.In the area of medical research, patients and families should have voices at all levels in shaping the research agenda, in determining how children and families participate in research, and in deciding how research findings will be shared with children and families.
6. Recognizing and building on the strengths of individual children and families and empowering them to discover their own strengths, build confidence, and participate in making choices and decisions about their health care.

Benefits of Patient and Family Centered Care[12]:

For patient and family:

- High-quality, patient- and family-centered primary care is associated with a significant reduction in non-urgent emergency department visits in children.
- Family presence during health care procedures decreases anxiety for the child and the parents. Research indicates that when parents are prepared, they do not prolong the procedure or make the provider more anxious.
- After redesigning their transitional care center in a way supportive of families, creating 24-hour open visiting for families, and making a commitment to information sharing, another children's hospital experienced a 30% to 50% decrease in the infants' length of hospital stay. Other outcomes included fewer re-hospitalizations, decreased use of the emergency department, greater parent satisfaction, and a decrease in maternal anxiety.

For Staff Nurses:

- Staff members have more positive feelings about their work than do staff members in an emergency department that does not emphasize emotional support. This may lead to improved job performance, less staff turnover, and a decrease in costs.

For Pediatricians

- Improved clinical decision-making based on better information and collaborative processes.
- An opportunity to learn from families how care systems really work and not just how they are intended to work.
- A possible decrease in the number of legal claims, claim severity, and legal expenses.

Family centered care In India: The Ministry of Health and Family Welfare, Government of India, has approved the adaptation and introduction of FCC in the public health services, and this initiative is supported by the Norway India Partnership Initiative under United Nations Development Programme (NIPI-UNDP) newborn project. Five demonstration sites at district Sick Newborn Care Units (SNCUs) have been set up namely at Alwar (Rajasthan), Raisen (Madhya Pradesh), Hoshangabad (Madhya Pradesh), Jharsuguda (Odisha) and Nalanda (Bihar).[13]

In 2015, the FCC (Family Centered Care) was set up in Alwar's district hospital in cooperation with the Norway India Partnership Initiative (NIPI).After testing Family Centered Care (FCC) in the district of Alwar, the

state health department of Rajasthan has now decided to expand the innovation to all 33 districts of Rajasthan. In addition to Rajasthan, the states of Bihar, Madhya Pradesh, and Odisha are also in the process of scaling up Family Centered Care (FCC) using existing government funds.[14]

A randomized control trial was conducted at the Post Graduate Institute, RML Hospital, New Delhi, during 2010-2012 with an aim to adapt principles of FCC to partly overcome the problem of human resource constraints and improve neonatal outcomes in a setting of a tertiary referral neonatal unit.[13]

Recommendations:

- Promote, introduce and expand the projects related to Patient and Family Centered Care in various institutions
- Aware the health care provider regarding importance of Patient and Family Centered care
- Parental Counselling and training regarding Patient and family centered care
- In hospitals, family members attending physician rounds,patient presentations and discussions in the patients' rooms with nursing staff should be standard practice.[5,6,7]
- In collaboration with patients, families, and other health care professionals, pediatricians should modify systems of care, processes of care, and patient flow as needed to improve the patient's and family's experience of care.

Conclusion

Patient and Family Centered care approach helps in increasing awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and well-being of their children. Health care professionals should modify systems of care, processes of care and patient flow as needed to improve the patient's and family's experience of care. This approach will help in enhancing the trust-based relationship between health care providers, patients and their families. Transparency in care and communication will reduce apprehensions and fears inherent with hospitalization.

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