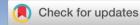


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Review Article



Aplication of Family Centered Care on the Impact of hospitalization in Intensive Care Unit In Parents' Perspective: literature Review

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Abstract

family-centred Care (FCC) is an effective intervention in reducing the impact of hospitalization. The aim of this literature review was to identify published research articles on the application of the FCC concept to the reduction of the impact of hospitalization in pediatric intensive care wards from the perspective of the parents. The literature review research took 14 journals from various databases published in 2015-2021. Searching for titles was obtained through identification and screening, entering inclusion criteria, so that 13 international journals and 1 national journal were obtained. The results of this study identified parental perspectives regarding the application of the core concepts of the FCC in reducing the impact of hospitalization, where each concept is accompanied by theme findings, for respect and dignity: a) the physical and cultural environment of the PICU, b) the expression of compassion and support from staff; sharing information: a) using understandable language, b) medical cycles, and c) satisfaction with communication; participation: a) parents as experts, b) how parents participate, c) environmental / staff impact on participation, and d) medical cycles; and Collaboration. This review reveals parents' reports that the implementation of the FCC concept in reducing the impact of hospitalization has not been fully fulfilled, as evidenced by the finding of positive and negative implementations related to the FCC concept.

INTRODUCTION

Children are individuals who are in a range of changes starting from infants to teenagers who experience changes in growth and development in a fast or slow time¹ Children can experience illness and even critical illness. Critical illness is a condition that is not expected and endangers the patient's life. These conditions can be in the form of acute illness, trauma and chronic disease. Critical

illness in children causes high morbidity and mortality rates.² In critical condition, children need intensive care.

The pediatric intensive care unit is a unit dedicated to treating pediatric patients aged over 28 days to 18 years who experience illness, accident/trauma, which is life threatening, requires intensive care, comprehensive observation, and special care³ his room includes most of the sophisticated and complex equipment such

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as intravenous lines, drugs, ventilators, monitors, and alarm sounds that are unusual for the patient's familv4 Hospitalization in the intensive care unit is a crisis for patients and families because of the emotional intensity experienced and the complexity of the care provided.⁵ The main stressors of hospitalization in children include separation, loss of control, bodily injury, and pain. The child's reaction to the stressor of hospitalization at separation showed that the child restrained the parent to stay (64.5%), the reaction to the loss of control was obtained by the child depending on the parent (64.1%) and the reaction to injury and pain was obtained by the child asking for action. ended (60.3%).6 Other studies have identified anxiety in parents that can arise as a response to alienated from the hospital being environment, such as not knowing the and the people it. room in not understanding medical rules and procedures, and feeling unable to control themselves and not being able to put themselves in a position to care for themselves. determine what role he must do while the child is in the hospital⁷ ⁸⁸<sup>8</su p>⁸⁸<sup>8</ sup>Families with children in intensive care units may experience significant psychological symptoms, including acute stress, post-traumatic stress, anxiety, and depression.9 Families with patients in critical care rooms experience Post Trauma Syndrome Disorder (PTSD) as much as 33%, 33% experience anxiety and 20% experience depression.¹⁰

Families are an important part of child care during illness. Creating a relationship between parents and health professionals is necessary, such as involving parents in making decisions and facilitating parental participation in child care¹¹ Increasing the role of parents in child care from an early age can reduce the negative impacts of hospitalization of children in intensive care.⁵

Family-centered care (FCC) as a model of care is a way of caring for children and their families in health services. 12 The Institute for Patient Family Centered Care developed four core concepts for implementing the FCC. namely respect and dignity: information sharing involves communicating and providing clear and unbiased information: participation includes family involvement in decisionmaking and child care; collaboration consists of partnerships with families to improve policies, programs infrastructure (https://www.ipfcc.org/).

The results of observations by researchers in the PICU room at a Semarang hospital, showed that parents with children who were treated in the PICU room waited more outside the room and experienced limitations in participating in caring for their children. The family feels anxious about the condition of their child in the intensive room without parental supervision. The partnership between the family and the health care team is very important in pediatric nursing. Parents are the constant voice, advocate and caregiver for the child. In addition, it is the parents who are most responsible for the care of the child after being discharged. The policy of family visits at the hospital makes parents or families have limited time in visiting hours, so they do not have 24-hour access to participate in caring for children. Families experience high levels of anxiety, stress and depression continuously. 13 The purpose of this literature review is to describe the perspective of parents in the implementation of FCC in the pediatric intensive care unit.

METHODS

This study can be classified as a literature review. The data based searches ScienceDirect, Springer Link, PubMed dan Google Scholar. The keywords used in the article search using 'Family Centered Care, Pediatric Intensive Care, Parents/family'. The search results obtained 13

international journals and 1 national journal with the year published between 2015-2021. The articles discussed in the literature review were obtained in the form of open access, relevant and free full text

with the theme of family centered care in the child intensive care room from the perspective of parents. The title search results can be seen in Figure 1

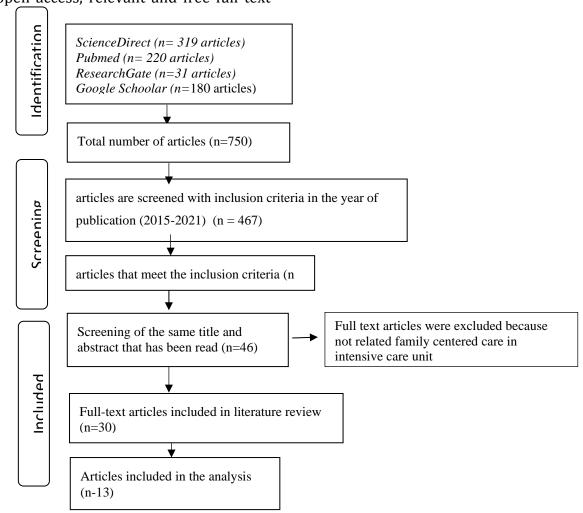


Figure 1. flowchart of screening articles

RESULT

Based on this literature review, there are four core FCC concepts, namely respect and dignity, information sharing, participation and collaboration. In this section, we will discuss the findings of the theme based on each of the FCC core concepts, about whether the application of the FCC core concepts has been applied in the PICU as a form of implementation to reduce the impact of child hospitalization in the eyes of the parents, which is summarized in table 2.

Tabel 1 Data Synthesis

No	Title. Researcher, year, journal source	Research design	Result	Conclusion		
1	Family-centered care and traumatic symptoms in parents of	Research design: Cross-sectional study Sample: 90 parents of children treated in	support from nurses is high in both parents and is associated with Acute Stress Disorder. 1/3 of parents have ASD. There were no significant gender differences when symptoms	Parents' traumatic experiences with child care in the PICU were associated with acute stress, but not disease		

No	Title. Researcher, year, journal source	Research design	Result	Conclusion	
	children admitted to PICU, ¹⁴ Scandinavian Journal of Caring Sciences	PICU in University Hospital of Aarhus. Method: Parents fill out a self-report questionnaire package when their child is discharged from the hospital	were dimensionally measured. If measured categorically, 17% of mothers and 7% of fathers suffer from ASD. Mothers with very young children had higher levels of acute stress; fathers whose children have high disease severity scores exhibit more acute stress	severity, or fear of losing the child. More research is needed to understand the dynamics of family- centered care	
2	Family presence during pediatric tracheal intubations (Sanders et al., 2016). Journal of JAMA Pediatrics	Research design: Prospective cohort study Sample: With or without family presence, all intubations of patients younger than 18 years in 22 international PICUs from July 2010 - March 2014 in the multicenter TI database (National Emergency Airway Registry for Children)	A total of 4969 tracheal intubations, 81% of intubations were performed with family present with a mean patient age of 2 years, 19% intubations were performed without family presence with a mean patient age of 1 year	Family presence was not associated with the success rate of tracheal intubation attempts or adverse events such as oxygen desaturation (<80%), or increased stress on the medical team. Data suggest that family presence during intubation can be safely applied as part of the FCC model in the PICU	
		Method: Comparing intubation actions on patients with family presence or without family presence			
3	3 Parental Research design: satisfaction with the quality of care in a South African paediatric and intensive care unit (Mol, Argent, & Morrow, 2018). Southern African Journal of Critical Care Research design: descriptive study Sample: 100 parents whose children were cared for in the PICU for 48 hours Method: Participants completed a questionnaire at the Children's Red Cross Hospital, South Africa (EMPATHIC-30), which includes 30 closed questions		Overall, parents reported positive experiences during their child's care in the PICU. However, the lowest response scores were found to be related to 'Information' and 'parental participation', which are important aspects of the FCC. active involvement of parents in decision-making about the care and treatment of their child as well as properly informing about the indications, effects and possible side effects of drugs, are highlighted areas for improvement of FCC practice in the PICU.	Although parents are generally very satisfied with the quality of care, increasing family involvement and providing adequate information in the PICU can contribute to the quality of the FCC.	
4	Parental Sources of Support and Guidance When Making Difficult Decisions in the Pediatric	Research design: prospective cohort study Sample: 86 English- speaking parents of 75 children in the pediatric intensive	Most parents choose doctors, nurses, friends and extended family as their main source of support and guidance when making difficult decisions	Parents rely heavily on doctors, nurses, and extended friends and family when making difficult decisions for their critically ill child	

	Title. Researcher,			
No	year, journal source	Research design	Result	Conclusion
	Intensive Care	care unit at Children'	s	
	Unit.	Hospital of		
	17	Philadelphia who		
	17	were hospitalized more than 72 hours.		
	The Journal of	Method: Each parent		
	Pediatrics,	completed the survey		
	1 00110101 100)	instrument		
		independently, and		
		team members were		
		present to answer		
	A 1''	any questions	Dili Dili C	D ': 1
5	A qualitative study of parents'	Research design: qualitative research	Riding a Roller Coaster is a core construct that describes the parental	Despite the exceptional medical services, parents
	experiences in the	Sample: 15 parents o		are traumatized by seeing
	pediatric intensive		four domains: being in a new stressful	
	care unit.	complex medical	situation, thinking hard all the time,	threatening situation and
		conditions who were	going through emotional storms,	being hit by a tidal wave of
	Alzawad, Lewis,	admitted for 48 hours		emotions. Parents live in a
	Kantrowitz-	or more in the PICU	people	state of uncertainty,
	Gordon, & Howells,	Method: Semi- structured face-to-		helplessness and fear, not knowing if their child will
	(2020)	face interviews were		survive or have a bad
	(2020)	conducted in the PICI	J	outcome such as
	Journal of	at the bedside of the	-	permanent disability.
	Pediatric Nursing	sick child		
6	Implementasi	Research design:	Generated 6 themes: meaning of	Strict regulations at PICU
	Perawatan	Qualitative	parents with children, perceptions of	prevent families from
	Berpusat Pada Keluarga.	phenomenology Sample: 12 people	parents and nurses, implementation, benefits, challenges, expectations of	participating in caring for their children in Picu
	Andra Saferi	consisting of nurses,	implementing family-centered care in	then children in ricu
	dkk.(2018)	parents and doctors	the PICU	
	Google scholar	by purposive		
		sampling		
7	Parents' Perceived		90% of parents believe that nurses	the availability of health
	Satisfaction of Care,	Cross-sectional, descriptive-	ignore their child's needs by not listening to parents and responding	professionals, the support and information they
	Communication	correlational design	slowly to their child's needs. Stepwise	provide to parents and
	and Environment	quantitative	regression analysis showed that the	children, are all important
	of the Pediatric	approach	number of hospitalizations, health	for parent satisfaction and
	Intensive Care	Sample: 123 parents	insurance and disease severity were	for a better quality of care.
	Units at a Tertiary		the main predictors of parental	
	Children's	hospitalized in	satisfaction	
	<i>Hospital.</i> (Abuqamar,	Amman		
	Arabiat, &			
	Holmes, 2016).			
	•			
	Journal of Pediatric Nursing			
8	Dominance of	Research design:	There are five themes: "non-owned	he prevailing atmosphere
	paternalism in	Etnographic	environment", "separation of children	in care is paternalistic
	family-centered	research design	from their parents," non-interactive	because there is a large
	care in the	Method: data	communication", "restricted	gap between the
	pediatric intensive		participation", and "combination of	conceptually or
	care unit (PICU): An ethnographic	participant observation, field	affection and sympathy".	theoretically accepted implementation of the FCC
	study	work, and		in the PICU and the
	stuuy	vv OI II, allu		in the rico and the

No	Title. Researcher, year, journal source	Research design	Result	Conclusion
	-	interviews with the main PICU actors, namely supervisors, nurses, and parents		applied FCC. Bridging the gap between theory and practice can help improve the social and organizational cultural environment for children, parents, and medical teams and their performance in PICU services
9	What Impact Do Hospital and Unit- Based Rules Have Upon Patient and Family-Centered Care in the Pediatric Intensive Care Unit?	Research design: Qualitative studies Sample: 7 parents of patients treated in PICU and 12 nurses Observation and interview	the existence of explicit and implicit rules in the pediatric intensive care unit, has a negative impact on the ability of families to receive care that is attentive to their needs	Agencies make rules and norms, which apply to nurses as service providers and families/patients as service recipients. However, there is a difference between what parents are looking for and what is provided by the staff as a result of the FCC's suboptimal implementation of institutional rules and norms. so a wider FCC model is needed.
10	Parents' experiences of their child being admitted to a paediatric intensive care unit: a qualitative study-like being in another world 21 Scandinavian Journal of Caring Sciences	Research design: Qualitative studies Method: Interviews were conducted on 12 parents whose child is being treated in the PICU	Parents' experiences of PICU care are summarized under the overarching theme of 'it's like being in another world. The analysis of the study led to the identification of two categories namely, 'engaged' and 'informed', with seven subcategories, namely caring for parents, security and trust, changing parental roles, stress and fear, importance of knowing interactions in care, preparation of information before action.	A parent's experience of having their child admitted to a pediatric intensive care unit is fraught with various emotions and fears. Good information, involvement and positive experiences of being transferred to the pediatric ward reduce stress and anxiety related to care in the PICU. The results of this study can be used as a basis for follow-up services for children and their families after treatment in the PICU
11	Elements of Family-Centered Care in the Pediatric Intensive Care Unit: An Integrative Review 22 Jurnal Physiology & behavior	Research desain: literature review	Five themes were identified: 1) information sharing; 2) hear the voice of parents; 3) make decisions for or with parents; 4) negotiating role; and 5) individual communication	PICU puts health staff in
12	An Evaluation of Family-Centered	Research desain: cross sectional	family and staff agree that medical team visits keep families informed and report positive statements	family and staff agree that medical team visits keep families informed and

No	Title. Researcher, year, journal source	Research design	Result	Conclusion
	Rounds in the PICU 23 Jurnal Pediatric Critical Care Medicine		regarding family presence at the time of visite; However, PICU colleagues disagreed that families provided relevant information and nurses reported that family presence limited discussion about patients. The main advice families offer providers to improve the well-being of medical team visits is to be more considerate and courteous, including adjusting family schedules, minimizing distractions, and limiting computer viewing.	report positive statements about family presence during visits; However, PICU colleagues disagreed that families provided relevant information and nurses reported that family presence limited discussion about patients. The main advice given by families to health workers to improve the goodness of medical team visits is to be more attentive and polite, including adjusting family schedules, minimizing distractions, and limiting computer viewing
13	The conceptualization of family care during critical illness in KwaZulu-Natal, South Africa. 24 Jurnal of Health SA Gesondheid	Research desain: qualitative Sample: 31 participants (family members, intensive care nurses and doctors) who voluntarily participated Data collection includes in-depth interviews	family care is conceptualized as togetherness, partnership, respect and dignity	During critical illness, the patient's family fulfills an additional important role for the patient who may be unconscious or unable to communicate or make decisions. Families not only provide vital support to their loved ones, but also become the "voice" of the patient
14	of children with chronic medical complexity during	Interpretive descriptive study Semi-structured interviews were conducted with 17 caregivers of 14 critically ill patients	Parents of patients with Chronic medical complexity (CMC) are expected to continue to provide care but feel that their knowledge and expertise is not always recognized by staff. They stress the importance of parent-staff partnerships. Four themes were identified: (1) "We know our child best;" (2) When skills collide; (3) Negotiating parenting boundaries; and (4) Importance is known. Results support the need for a PICU parenting approach for CMC that recognizes parental expertise	Partnership between staff and parents, good communication with staff, continuous attention in the PICU are very important, especially in the case of CMC

Tabel 2
Summary of Journal Description (n = 14)

FCC concept	theme	parents' perception	n	%	Reference	
Respect and	Perception of the	the bathroom in the unit and the	5	35	18	
dignity	physical	waiting room furniture are not			- (Mol, Argent, &	
	environment and	available. Noise level in the PICU,			Morrow, 2018),	
	trigger culture	small room size, comfortable chair				
		near the patient's bed, facilities for				

FCC concept	theme	parents' perception	n	%	Reference
		meeting parents' personal needs (cleaning, nutrition, rest)			- (Alzawad, Lewis, Kantrowitz-Gordon, & Howells, 2020). - 19 - (Baird, Davies, Hinds,
					Baggott, & Rehm, 2015)
	Expressions of affection and support from the staff	Expressions of affection and support from the staff	8	57	- Madrigal et al., 2016) - (Mortensen et al., 2015) - (Alzawad et al., 2020); - (Dahav & Sjöström-Strand, 2018) - (Sanders et al., 2016) 19 - (Levin, Fisher, Cato, Zurca, & October,
					2015a)
Sharing information	Use a language you can understand	Difficult terms, absorption of information, parent's choice of language, misunderstood	3	21	-26 -(de Beer & Brysiewicz, 2017)(Alzawad et al., 2020; Baird et al., 2015).
	Visit the medical team	Parents can receive information, feel accepted, feel opinionated, can ask questions, feel reassured, transparency, cause stress, discomfort and anxiety	3	21	- (Levin et al., 2015a) - ²⁷ - (Levin et al., 2015a).
	Satisfaction with communication	Satisfied with feedback, easier to get information, introduced to staff. Dissatisfied when staff speak coldly, ignore emotional and spiritual needs, poor admissions, disparate information, too many staff	7	50	- (Richards, Starks, O'Connor, & Doorenbos, 2017) - (Levin et al., 2015a; - Rennick et al., 2019)16 - Abuqamar et al., 2016 - Vasli et al., 2015) - Saferi Wijaya et al., 2018)
Participation	parents as experts	Staff: treats parents as experts, accepts advice, asks for consideration, puts it into practice, Parents: feel unheard, hesitate to express opinions, worry about disturbing	5	35	_25,28 18-20
	How Parents participate	Parents look after children, are involved in care, entertain children, as child advocates	5	35	-(Abuqamar et al., 2016; 2015; -Rennick et al., 2019 -(Baird et al., 2015)
	Environmental/s taff impact on participation	Staff guiding parents Parents have limited participation, because of the PICU rules, the trigger environment is not child-friendly	4	28	-(Mortensen et al., 2015). -(Baird et al., 2015) - ¹⁸
	Visit the medical team	As an avenue for participating in treatment decision making, equate perceptions in participation	2	28	-(Richards et al., 2017) -(Levin et al., 2015)

DISSCUSION

Based on a review of the identified literature, it provides an overview of the application of the FCC core concept as an intervention to reduce the impact of hospitalization on children in the PICU in the view of parents.

The concept of respect and dignity with the theme of the perception of the physical and cultural environment of the PICU and expressions of compassion and support from staff. The physical condition of the PICU environment is a factor that influences parents in getting respect and dignity. Parents' perception that a clean and comfortable room, close to the waiting room is an indicator of respect. 18 The lack of communicated respect was unavailability of a bathroom for the family, so that during a visit the parents had to leave the PICU to find a bathroom, then return to the unit which had to pass through the security guard/door with an automatic lock button. 16,27 Parents, expressed other indicators of a lack of respect due to noise levels in the PICU, disrupting rest, small size, insufficient space accommodate personal items or providing a comfortable chair near the patient's bed. 18,27 there are no facilities for parents to meet their personal needs such as cleanliness, nutrition, or a place to rest.¹⁹ In the pediatric intensive care unit, parents comment that the waiting room is generally an uncomfortable social space where stressed family members exhibit various emotional behaviors and annoy other patients' families.²⁰ One report describes waiting room furniture that is not conducive sitting resting.¹⁶ Having or environment where parents can be present, make unlimited visits, perform basic activities of daily living and fulfill their own hygiene needs, and feel comfortable, safe, and welcome is a basic form of respect and dignity that every parent should give when their child is in the PICU as a form of implementation of the FCC concept in reducing the impact of hospitalization. Children's room environment is considered by parents to affect their ability to physically participate in child care, in order for parents to be active in care, staff should explain to parents about equipment installed in children and how parents can safely touch, hold, and participate in care. Equipment placement can be modified so that parents can physically reach the side of the bed to care for the child.

The concept of sharing information, related themes are using understandable language, medical team visits, and satisfaction with communication. Information sharing is defined as health workers communicating and sharing complete and unbiased information with patients and families. Patients and families receive timely, complete, and accurate information to participate effectively in care and decision making. For parents, the most important aspect of communication is that the doctor uses language that the family understand²⁶, shows that the speed with which information is provided is important for the patient's family in absorbing information, considering the stress, fatigue, and emotions caused by the information itself ²⁴ Several parents indicated that the terms used by the health team led to a misunderstanding of the severity of the child's illness, or why certain procedures performed.^{20,27} **Parents** were not recommend that when communicating with families where multiple languages are spoken, staff should communicate in the parent's preferred language as a sign of respect and to maximize understanding.

Regarding the Medical Team Visit or better known as the doctor's visit in the pediatric intensive care unit, it is an opportunity for parents to participate and be an active part of exchanging information about their child's care. Parents' experiences with doctor visits relate to information sharing

and participation. Based on the results of previous studies, 74% of family members reported having received information about the medical round, 92% felt accepted, 97% felt that listening to child case discussions by the provider team was very helpful, 92% felt comfortable asking questions, parents also reported that participating in the medical round about their child provides an opportunity to receive and exchange information with the team.²⁶ Although parents are not happy to be in the PICU and see their child being monitored intensively, they believe this is the kind of care their child needs, which gives them "a little peace of mind". Parents feel "reassured" when surrounded by the medical team during a doctor's visit to discuss the child's case and treatment plan.²⁷ Although parents reported that listening to the various treatment options discussed during the medical round was stressful and uncomfortable participating in these activities, 36% believed doctor visits promoted transparency between parents and the care team. Parents report feeling anxious about the information they hear.26

Regarding the theme of satisfaction in communicating, parents expect and need regular and frequent feedback about their child's progress and condition.²⁸ Parents indicated that they know their child best, part of the role of parents is to obtain information about their child's care and condition.^{25,26} **Parents** expressed satisfaction and dissatisfaction about communication with the service team in the PICU. In the intensive care unit, parents reported that it was easier to get information such as doctor's visit schedule than in other wards because the ratio of nurses to patients was one to one. The parents said "The doctor immediately informed me about the procedure to be performed". "We can ask any questions and they are willing to answer." "We were introduced to the staff and got complete information about our son's condition."16 Parents reported that they were introduced to service staff. Doctors and nurses communicated well, answered questions thoroughly, staff immediately informed parents about the procedure to be performed.^{16,18}

n contrast to those who expressed satisfaction with communication, parents were dissatisfied when staff spoke coldly ignored their emotional needs.19 psychological Other parents reported that the staff did not do a good job of preparing them for hospitalization in the PICU.¹⁸ Para orang tua melaporkan mendapatkan informasi yang konsisten dari berbagai staf layanan, yang menyebabkan kebingungan dan frustrasi. Parents reported getting inconsistent information from various service staff, leading to confusion and frustration. Parents report receiving disparate information or among service staff they think there are too many staff involved in care to know what others are doing. 25,28,29 Although there are several reports of examples of communication considered poor, the implementation of good information sharing is mostly fulfilled from the perspective of parents with children who are being cared for in intensive care.

Reducing the impact of hospitalization on parents with children being treated in the PICU, there is a need for continuous of understandable communication information to parents of children in the PICU, validating that what the family "hears" is what the provider wants to for clarification convev. and misunderstandings. Repeating information in multiple formats (oral, written, or visual demonstration), and using simple, familyunderstandable terms in the family's language of choice, and then verifying that understand the information parents correctly, can help exhausted parents absorb a lot of the information, complex information they provide when stressed.

The concept of participation, discusses the theme of parents as experts, how parents participate, the impact of the environment/provider on participation, and visits to the medical team as a forum for participation. Some parents view participation in medical team visits as a means to exchange information with the health care team. However, some parents refuse to participate in medical team visits due to confusion or anxiety, in which case staff must find other ways to share information with parents. Parental participation in medical rounds should not replace the individual's frequent exchange of information with the family. Treating parents with respect includes respecting their decision whether to participate in the medical round and determining what alternative opportunities are available to them to participate in care and exchange information with staff. parents should be encouraged and supported to participate in care at the level of their choosing. The key is a shared understanding between parents and providers of how, when, and the amount of participation each parent wants. Develop a plan for parental participation re-evaluate it from time to time to find out what level of participation they desire. This is expected to reduce the impact of stress experienced by parents.

On the concept of collaboration as defined by the IPFCC there are no data showing its implementation in the summarized literature review. There is no evidence that parents reported having been involved in efforts with health care institutions or health care systems about policy and program development, facility design, and education.

CONCLUSION

The application of the FCC is a benchmark in caring for pediatric patients and their families. Parents of children who are admitted to the PICU often relate to the severity of their child's illness and how to treat their child in the PICU environment

which results in different levels of anxiety or stress. The findings from this literature review reveal parental reports that the application of FCC in reducing the impact of hospitalization has not been fully realized. There are still positive and negative implementations related to the FCC concept. The medical services team must be aware of the FCC's core concepts and how their actions can impact parents in both positive and negative ways.

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