

## THE EXPERIENCES OF PARENTS IN FAMILY CENTERED CARE FOR CHILDREN IN HOSPITAL: A LITERATURE REVIEW

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### Abstract

**Introduction:** Hospitalization is a condition that causes anxiety in children and parents. Most parents experience mild stress (68.0%) while children experience anxiety disorders (60-80%). Pediatric nurses to provide further care in facilitating optimizing Family Centered Care (FCC) through the provision of health education and ongoing assistance from initial hospital admission to recovery from discharge to reduce the impact of the hospital on children in hospital. This article aims to identify and discover the family's experience of family centered care for children who have been hospitalized.

**Method:** A literature review using PRISMA by collecting the results of scientific publications in the period 2014 to 2022 obtained from PubMed, ProQuest, Science Direct and secondary searches. Then the articles were screened according to the inclusion criteria.

**Results:** In this literature review, 4 clinical studies were identified that matched the criteria for research on family-centered care in children. There are 3 qualitative studies and 1 study using a cross-sectional study.

**Conclusion:** Parents have obstacles in the application of family centered care. Family centered care can improve parental skills and reduce parental anxiety in caring for children in hospital.

**Key words :** *Family Centered Care; Hospitalization; Parents; Experiences*

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### INTRODUCTION

Hospitalization is a condition that is experienced by children, from infants to teenagers. According to Wong in Timiyatun & Hariyanti (2018) the impact of hospitalization is feeling hopeless, causing protest reactions, being uncooperative and depressed. Wong said the impact of hospitalization on children arises from separation, loss of control and pain. Hospitalization has a negative impact on children which causes anxiety. The cause of children experiencing anxiety and stress is influenced by several factors, namely from health workers who accompany during treatment and the new environment.

Hospitalization also has an impact on parents who experience the same anxiety as experienced by children. Parents feel anxious because they think about the safety of their children and see that their children are equipped with many tools and invasive measures are being carried out. In general, the parent's response to the hospitalization of a child includes: distrust, anger, guilt, fear, anxiety, stress, and frustration. This is supported by research Idris & Hartati (2016) which found that the stress level of parents mostly experienced mild stress (57.5%) and a small portion of severe stress (42.5%). The prevalence of anxiety disorders that occur in children while in hospital ranges from 60-80% of the general population (Juwita, 2019).

Pediatric nurses as a profession whose job is to provide nursing care to children have a very important role in facilitating parents to optimize Family Centered Care (FCC) through the provision of health education and ongoing assistance from the beginning of hospital admission to preparation for returning home (Yugistyowati, 2018). According to the American Academy of Pediatrics (2012) in Suza (2016) FCC is the most important thing in child hospitalization which is based on collaboration between children, parents, doctors, nurses, and other professionals in clinical care based on planning, providing interventions and evaluating health services. FCC aims to maintain and strengthen the role of families and emotional bonds with children (Festini, 2014).

FCC can improve clinical decision making based on better information and collaborative processes,

increase follow-up when a treatment plan is developed together with families, be more efficient and effective in the care process, improve communication between health team members and increase professional satisfaction (Suza, 2016). In this regard, the development of the FCC is an important key to reducing the impact of hospitalization on children in hospitals. Therefore, this article aims to identify and evaluate family experiences with FCC in children who have been hospitalized.

### **METHOD**

The rules for making this review article are based on the 2009 PRISMA checklist (Moher et al., 2009).

#### **Search Strategy**

The search strategy was carried out by searching for several studies found through the database, namely the PubMed, ProQuest, Science Direct and secondary searches. This strategy uses a combination of title/abstract terms. The research questions were designed using the PICO principles. The PICO review questions consist of Population (Inpatient OR pediatric hospitalization), Intervention (Family centered care OR FCC), Comparison (None), Outcomes (Parental experience AND family centered care outcomes).

#### **Inclusion Criteria**

The selected studies were published from 2014 to 2022. The year 2015 was chosen as the starting point for the literature search for expansion because the search in the previous year published articles on family centered care in children aged 0-12 years undergoing hospitalization with a qualitative study by Watts et al (2014). The study search was conducted on June 12, 2022. In addition to the database, a manual search was conducted to find studies relevant to the keyword articles. Studies were eligible if they met the inclusion criteria are all types of research studies, published in 2014-2022, published in full text and in English, and studies of family centered care of various diseases experienced by hospitalized children.

#### **Data Extraction and Quality Assessment**

Extraction includes: researcher, year, place of study, method, objectives, participants, outcome measurement, and study results. Meanwhile, to assess the quality of each, the authors criticize qualitative article studies using the tools of the Critical Appraisal Skills Program (CASP) Qualitative research (Critical Appraisal Skills Program, 2013) while cross sectional article studies use tools from the Center for Evidence-Based Management (CEBM, 2014).

#### **Study Characteristics**

The total search results for articles from several databases are 408 articles. Then screened into 159 articles based on the inclusion criteria. The number of articles that match the research questions and inclusion criteria is 4 articles. In this literature review, 4 clinical studies were identified that matched the criteria for research on family centered care in children. There are 3 qualitative studies (Finlayson et al., 2014; Moore et al., 2015; Serlachius et al., 2018) and 1 study using a cross-sectional study (Shimizu, 2018). The four articles were not intervening and constitute an article based on the experience of mothers who had children who were hospitalized. 3 research articles were conducted in the NICU, and 1 was conducted in the pediatric ward. All studies have a FCC approach and are not interventioned.

#### **Experience**

In qualitative research, there are several different themes. According to research conducted by Serlachius et al (2018) in Auckland New Zealand, the identified themes center on the challenges parents feel with FCC from admission to hospital discharge. Three main themes were identified, namely powerlessness, hierarchy between parents and staff and the peripheral role of fathers. The first theme (helplessness) focuses on factors in the NICU that contribute to parents feeling powerless in their role as caregivers. Parents feel frustrated because they are not allowed to read files or medical records about their babies and are not close to their babies. The second key theme describes the hierarchy or gap between parents and NICU staff. This gap is often exacerbated by the busy NICU environment and limited access to the NICU. The third theme is the role of the peripheral father. Father finds it difficult to carry out his

role as a second person after mother and the main support because it is controlled by the environment in the NICU.

## RESULTS

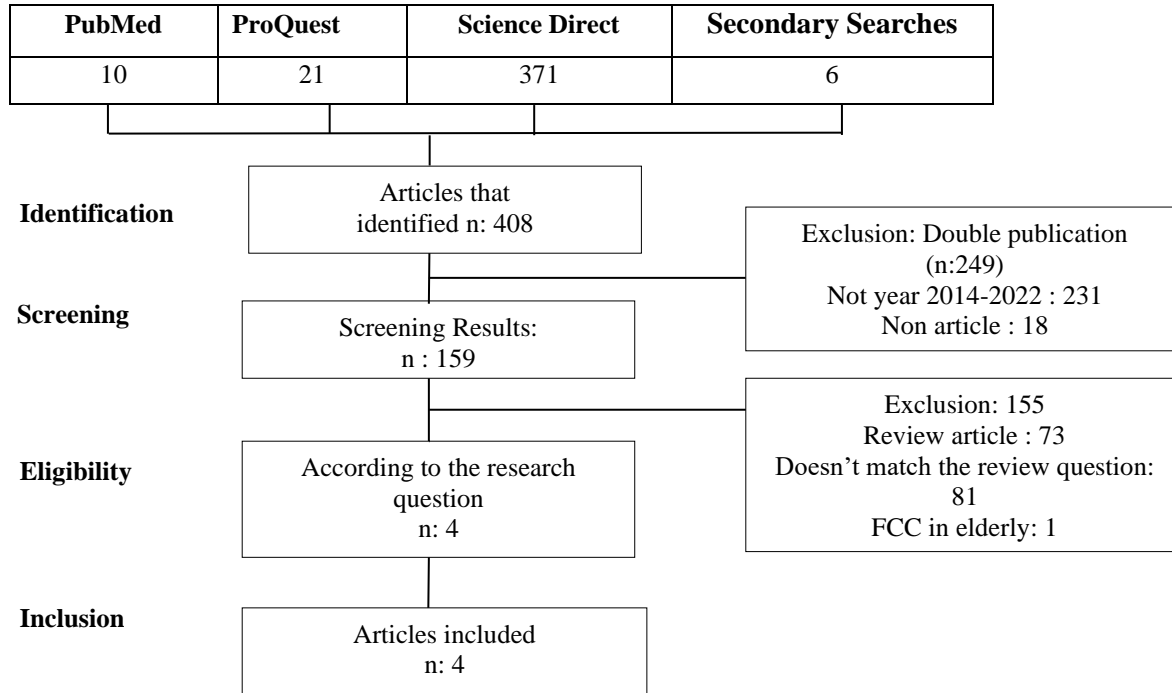


Figure 1. Search Algorithm

Table 1. Sintesis Grid

No	Researcher, City	Method	Aim	Partisipant	Outcome measurment	Outcome
1	Serlachius, et al (2018), New Zealand's.	Qualitative research design: Interviews during hospital admission and discharge	to examine the experiences of parents from the FCC during hospital admission and discharge, their perceptions of NICU staff, how informatio	83 parents namely 63 mothers and 20 fathers of premature babies in the National Women's Health NICU.	Parental and infant characteristics were assessed in the initial questionnaire or extracted from clinical records. The questions are not asking about the FCC but more about treatment in general. Interviews were hand-recorded by J Hames (verb recording) and written directly after each interview. The decision not to record audio was to	Three main themes (and sub-themes) were identified: powerlessness, hierarchy between parents and staff and the peripheral role of fathers. The challenges related to FCC reported by parents upon admission and discharge represent some of the main barriers parents still face in terms of being fully involved in the care of their infant in the NICU.

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		n received and their suggestions for improving care in the NICU.		allow participants to freely provide feedback on their experience in the NICU. Qualitative data analysis using theoretical thematic analysis (deductive approach).		
2	Shimizu & Cross Mori (2018), Japan.	Cross sectional study	to evaluate maternal perception of FCC in hospitalized preterm infants.	98 mothers whose babies are being cared for in the NICU.	using two standard revisions questionnaire in Japanese: Measure of Process of Care in the NICU (Neo-MPOC 20), Enabling Practice Scale in the NICU (Neo-EPS), and the author developed Mother and Infant Questionnaire.	Maternal perceptions of FCC with hospitalized preterm infants were better promoted. As many as 48.9% of mothers visited their babies comfortably and 40.8% were able to make contact. Mothers' perceptions were almost always positive, but indicated a lack of opportunity to share information.
3	Moore, M et al (2015), Washington.	Qualitative method with semi-structured interview	explores the experience of families undergoing pediatric Trauma Brain Injury (TBI) care to identify the specific factors and barriers associated with FCC.	Mothers of children under 18 years who were treated for TBI in the past 5 years. Sampling using purposive sampling. The number of participants is 15 people.	Content analysis was used to code the transcribed interviews and develop a family-centered care model.	The parental experience is that all parents spend a lot of time at the bedside during their child's hospitalization, each having opportunities to interact and communicate with staff. Three main themes emerged: 1) thorough, timely, compassionate communication, 2) capacity building for families, providers, and facilities, and 3) coordination of care transitions. Thorough and timely communication can reduce family anxiety.
4	Finlayson et al (2014), UK.	Qualitative	To explore maternal perception of FCC in the neonatal intensive care unit (NICU) in	12 mothers from 3 NICU in the UK were obtained using individual interviews.	A central global theme supported by a number of organizing themes was developed to reflect the views of mothers and their experiences with the FCC.	This finding obtained a global theme, namely finding my place which consists of six, namely mothering in limbo, deference to the experts, anxious surveillance, muted relations, power struggle, consistently inconsistent. Mother

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UK.

experiences a limiting role in the NICU.

Table 2. CASP Qualitatif

No	Appraisal Checklist	Serlachius et al (2018)	Moree et al (2015)	Finlaysona et al (2014)
1	Aims of the research	yes	yes	yes
2	Methodology appropriate	yes	yes	yes
3	Research design appropriate	yes	yes	yes
4	Recruitment strategy appropriate	yes	yes	yes
5	Data collected in a way that addressed the research issue	yes	yes	yes
6	Relationship between researcher and participants been adequately considered	yes	yes	yes
7	Ethical issues been taken into consideration	yes	yes	yes
8	The data analysis sufficiently rigorous	yes	yes	yes
9	A clear statement of findings	yes	yes	yes
10	Valuable	yes	yes	yes

Table 3. Cross Sectional

No	Appraisal Checklist	Shimizu (2018)
1	Did the study address a clearly focused question / issue?	Yes
2	Is the research method (study design) appropriate for answering the research question?	Yes
3	Is the method of selection of the subjects (employees, teams, divisions, organizations) clearly described	Yes
4	Could the way the sample was obtained introduce (selection) bias?	Yes
5	Was the sample of subjects representative with regard to the population to which the findings will be referred?	Yes
6	Was the sample size based on pre-study considerations of statistical power?	Yes
7	Was a satisfactory response rate achieved	Yes
8	Are the measurements (questionnaires) likely to be valid and reliable?	Yes

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9	Was the statistical significance assessed?	Yes
10	Are confidence intervals given for the main results	Yes
11	Could there be confounding factors that haven't been accounted for?	No
12	Can the results be applied to your organization?	Yes

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According to research by Moore et al (2015) in Washington, three main themes emerged, the first theme was thorough, timely communication, the second theme was capacity building for families, providers, and facilities, and the third theme was coordination of care transitions. The parental experience with the FCC is that all parents spend a lot of time at the bedside during their child's hospital stay, each having ample opportunities to interact and communicate with staff. In addition, staff's thorough and timely communication to families reduces family anxiety.

Meanwhile, according to research by Finlayson et al (2014) in the UK, the global theme is finding my place which consists of six, namely mothering in limbo, deference to the experts, anxious surveillance, muted relations, power struggle, consistently inconsistent. This finding found that the mother experienced a state of liminality and was very sensitive to power struggles, awkward relationships and inconsistencies in care. To try to maintain their balance and protect their babies, they form harmonious relationships with healthcare professionals and stay under close supervision.

In a cross-sectional study by Shimizu (2018) in Tokyo Japan, mothers' perceptions of FCC with hospitalized premature babies were promoted better. As many as 48.9% of mothers visited their babies comfortably and 40.8% were able to make contact. Mothers' perceptions were almost always positive, but indicated a lack of opportunity to share information.

### DISCUSSION

This review article focuses on parental experiences of family centered care for parents. Parents' experience of family-centered support with hospitalized children promoted better collaboration between mothers and nurses to acquire parenting craft skills. The more mothers involved in the care of their hospitalized child, the lower their risk of depression, the greater their mother's role identity and confidence in caring for their child.

Mothers who are involved in the FCC have a better level of comfort because they are beside their children during treatment and improve communication with health care staff in the room. This can also reduce parental anxiety, especially in the NICU. Mother's perception of family-centered support with hospitalized preterm infants promoted better collaboration between mothers and nurses to gain parenting craft skills Shimizu (2018).

However, from some of these experiences, parents still face significant barriers to the FCC. Challenges related to FCC reported by parents upon admission and discharge are some of the main barriers parents still face in terms of being fully involved in their child's care. Parents need the same amount of support during their hospital stay. Parents need more information and feel like getting involved in their baby's care as this helps them feel more in control and less anxious in a highly stressful and uncertain environment. Therefore, it is necessary to support parents in FCC services to improve outcomes such as parental skills in caring for their children during hospitalization to returning home, reducing anxiety and improving communication with health care staff at the hospital.

### CONCLUSION

Parents have obstacles in the application of family centered care. Family centered care can improve parental skills and reduce parental anxiety in caring for children in hospital. Family-centered implementation may be a turning point to support parents more effectively in assisting in the care or improvement of children's health.

### REFERENCES

- CEBM. (2014). *Critical Appraisal of a Cross-Sectional Study (Survey) Appraisal questions*. 2014.
- Critical Appraisal Skills Program. (2013). Critical Appraisal Programme (CASP): Qualitative research checklist. *Dept. of General Practice, University of Glasgow, 2017*, 1–6. <https://doi.org/10.1111/j.1600-0447.1980.tb10232.x>
- Festini, F. (2014). Family-centered care. *Academic Pediatrics, 11*(2), 97–99. <https://doi.org/http://dx.doi.org/10.1016/j.acap.2010.12.004>
- Finlayson, K., Dixon, A., Smith, C., Dykes, F., & Flacking, R. (2014). Mothers' perceptions of family centred care in neonatal intensive care units. *Sexual and Reproductive Healthcare, 5*(3), 119–124. <https://doi.org/10.1016/j.srhc.2014.06.003>
- Idris, M., & Hartati, S. (2016). *Hubungan Hospitalisasi Anak dengan Tingkat Kecemasan Orang Tua di Ruang Anak RS Thamrin Salemba Jakarta Pusat Tahun 2016*. 49–54.
- Juwita, H. (2019). Effectiveness of Multimodal Interventions Play Therapy: Colouring and Origami Against Anxiety Levels in Toddler Ages. *Journal of Health Science and Prevention, 3*(3S), 46–51. <https://doi.org/10.29080/jhsp.v3i3s.288>
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Annals of Internal Medicine, 151*(4), 264–269. <https://doi.org/10.1371/journal.pmed1000097>
- Moore, M., Robinson, G., Mink, R., Hudson, K., Dotolo, D., Gooding, T., Ramirez, A., Zatzick, D., Giordano, J., Crawley, D., & Vavilala, M. S. (2015). Developing a family-centered care model for critical care after pediatric traumatic brain injury. *Pediatric Critical Care Medicine, 16*(8), 758–765. <https://doi.org/10.1097/PCC.0000000000000494>
- Mortensen, J., Simonsen, B. O., Eriksen, S. B., Skovby, P., Dall, R., & Elklit, A. (2015). Family-centred care and traumatic symptoms in parents of children admitted to PICU. *Scandinavian Journal of Caring Sciences, 29*(3), 495–500. <https://doi.org/10.1111/scs.12179>
- MS. AYA SHIMIZU. (n.d.). 0–2. <https://doi.org/10.1111/ijlh.12426>
- Serlachius, A., Hames, J., Juth, V., Garton, D., Rowley, S., & Petrie, K. J. (2018). Parental experiences of family-centred care from admission to discharge in the neonatal intensive care unit. *Journal of Paediatrics and Child Health, 54*(11), 1227–1233. <https://doi.org/10.1111/jpc.14063>
- Shevell, M., Oskoui, M., Wood, E., Kirton, A., Van Rensburg, E., Buckley, D., Ng, P., & Majnemer, A. (2019). Family-centred health care for children with cerebral palsy. *Developmental Medicine and Child Neurology, 61*(1), 62–68. <https://doi.org/10.1111/dmcn.14053>
- Suza, D. E. (2016). Family-Centered Care Model untuk Menurunkan Dampak Hospitalisasi Anak dengan Penyakit Kanker di Medan , Sumatera Utara Family-Centered Care Model to Reduce Impact of Hospitalization Children with Cancer in Medan , Sumatera Utara Dewi Elizadiani Suza. *Idea Nursing Journal, VI*(I), 15–24.
- Timiyatun, E., & Hariyanti, S. (2018). *Hubungan Penerapan Family Centered Care oleh Perawat dengan Stres Orangtua Selama Hospitalisasi Bayi*. 2(3), 89–96.
- Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., & Ngune, I. (2014). Family-centered care for hospitalized children aged 0-12 years: a systematic review of qualitative studies. *JBIC Database of Systematic Reviews and Implementation Reports, 12*(7), 204–283. <https://doi.org/10.11124/jbisrir-2014-1683>
- Yugistyowati, A. (2018). Penerapan Family Centered-Care (Fcc) Terhadap Keterampilan Orang Tua Dalam Perawatan Bayi Prematur. *Media Ilmu Kesehatan, 5*(2), 119–127. <https://doi.org/10.30989/mik.v5i2.60>