

Parents' Perception regarding Their Participation in the Care of Hospitalised Children at a Tertiary Government Hospital in Blantyre, Malawi

Lophina Sitima Phiri

<https://orcid.org/0000-0002-6550-7334>

Paediatric and Child Health Association
of Malawi

C/O College of Medicine, Malawi

phirilophina@gmail.com

Angela F. Chimwaza

University of Malawi

afchimwaza@kcn.unima.mw

Patrick G.M.C. Phiri

<https://orcid.org/0000-0001-6035-9101>

Saint John of God College of Health
Sciences, Malawi

patrickgmcpheiri@yahoo.co.za

Abstract

Parental participation is one of the cornerstones of paediatric practice. Evidence from the literature has shown that effective parental participation depends on parents' preparedness, adequate communication between parents and nurses, and the negotiation process. However, little is known about the perception of these parents regarding their participation in the care of their hospitalised children. The aim of the study was to explore the perceptions of parents regarding their participation in the care of their children who were hospitalised at a government hospital in Malawi. A descriptive qualitative study was carried out using a semi-structured interview guide to collect data from 20 parents in the paediatric department. Thematic analysis was done guided by Colaizzi's method. Three main themes emerged from the data and these were lack of role negotiation by healthcare workers, inadequate role preparation for parents, and parents' perceptions of the care they provided to their hospitalised children. The study findings showed that parents view their participation in the care of hospitalised children as appropriate, important and satisfying. However, gaps exist in the way they participate in the care of their hospitalised children due to inadequate role negotiation and role preparation for parents and inadequate information from nurses. The researchers recommend that management should

develop protocols and guidelines for the implementation of parental participation in the care of hospitalised children to promote best practices and quality children's care.

Keywords: hospitalised children; role preparation; negotiation; parental participation; Malawi

Introduction and Background

Parental participation (PP) is one of the core concepts of family-centred care (FCC), which forms the framework for paediatric nursing care. The other components include collaboration, information sharing and treating families with respect and dignity (IPFCC 2013). There is evidence that PP in the care of hospitalised children is beneficial to both parents and children (Vasli and Salsali 2014, 144). As such, allowing parents to participate in caring activities alleviates anxiety for both parents and children and promotes the emotional welfare of children. In addition, through PP parents experience the continuity of their parental role and acquire enhanced coping skills (Ames, Rennick, and Baillargeon 2011, 143). Furthermore, PP reduces the workload of the nurses (Coyne 2015, 799). It also helps in the provision of the best care possible for hospitalised children (Priddis and Wells 2010, 22–23). Parental participation is therefore viewed as an essential element of quality care for hospitalised children (Abdelkader et al. 2013, 1–2).

Studies have shown that parents desire to participate in the care process and decision-making, but both nurses and parents experience problems in this context (Ames, Rennick, and Baillargeon 2011, 144). There is variability in how PP is implemented; in some cases parents take a passive role and in others they are given total responsibility for the care of their children (Ames, Rennick, and Baillargeon 2011, 149). This suggests that role preparation, good communication and negotiation between parents and nurses are paramount (Zhou et al. 2012, 391). Studies have shown that role preparation, negotiation of care roles, and communication between parents and nurses do not routinely take place (Vasli and Salsali 2014, 137). PP needs to be individually negotiated and mutually agreed upon with every parent (Vasli and Salsali 2014, 144). However, little evidence exists on how parents are prepared for their role, how the parents' caring roles are negotiated and to what extent information is shared among nurses and parents of hospitalised children in Malawi. This study explored the perceptions of parents regarding their participation in the care of their hospitalised children at a tertiary hospital in Malawi.

Review of Literature

Parents' Perception of Their Participation in the Care of Their Hospitalised Children

Parents view their children's hospitalisation as a very critical event, regardless of the child's condition and period of hospital stay (Abdelkader et al. 2013, 356). Haskel et al. (2012, 66) found that mothers felt their role was to perform the mothering tasks. Mothers indicated that to them mothering meant doing things that they would normally do when at home, such as changing nappies, giving fluids, and stopping the child from getting out of the cot. They also felt that they had to be watchful of the child removing the intravenous line, whereas nurses ensured that the child received the correct amount of medication, did dressings and prepared intravenous fluids. Mothers view technical care as solely the responsibility of the nurses. This is because nurses have knowledge and expertise from their training. Ames, Rennick, and Baillargeon (2011, 144) showed that parents were willing to provide basic childcare, but were generally reluctant and anxious to perform technical nursing care due to their lack of knowledge about medical and nursing matters, which could cause harm to their children. Al Momani (2011, 1) found that in Jordan mothers provided both basic care and technical care and they felt confident and comfortable with all the care they were providing to their children. This implies that parents value participating in the care of their hospitalised children.

Role Negotiation between Parents and Nurses in Parental Participation

Parental participation requires a process of negotiation between nurses and parents which results in shared decisions (Mikkelsen and Frederiksen 2011, 1552). According to Mikkelsen and Frederiksen (2011, 1554), the negotiation of caring roles allows parents to feel in control of what their participation in their children's care will entail. Studies show that nurses make assumptions that if parents are available in the hospital they would be willing to participate in the care of their hospitalised children (Jones et al. 2017, 1–2). However, decisions to determine the level of parental participation still rest entirely with the nurses, with little or no consultation or negotiation with the parents. This may suggest that the nurses control the nature of parental participation. Studies also show that culture has an influence on parental participation (Harrison 2010, 340; Mackay and Godfrey 2011, 49). Abdulbaki, Gaafar, and Waziry (2011, 316) compared the cultural differences between Chinese parents and parents in Western countries in terms of communication and ways of giving support and seeking care. The results showed that Chinese parents participated in the care of their children not by choice but because the circumstances in the hospital, such as a shortage of nurses compared to Western counterparts, demanded it. In some instances, parents do not have any choice but to participate because of a shortage of staff (Harrison 2010, 341). This suggests that parental participation was regarded as a means of relieving the hospital staff of their workload. Thus this made the negotiation of aspects in PP far less feasible. In summary, the literature shows that parental participation is considered a desirable practice by the parents. Studies have described how parents participate in the care of their hospitalised children (Abdulbaki, Gaafar, and Waziry 2011, 317; Coyne 2015, 799–801; Harrison

2010, 336; Jolley and Shields 2009, 166; Mackay and Godfrey 2011, 50). However, differences exist in terms of how parents perceive their participation, how nurses prepare parents for their roles and how these caring roles are negotiated during the period of hospitalisation of the child.

Significance of the Study

In Malawi, little is known about how parents participate in the care of hospitalised children. The study findings may influence policymakers to formulate policies and guidelines on parental involvement in the care of children during hospitalisation in Malawi. The study findings may also serve as a basis for future research.

Study Objectives

The specific objectives of the study were, firstly, to describe how caring roles are negotiated between nurses and parents caring for hospitalised children, and secondly, to identify parents' perceptions regarding the care they provide to their hospitalised children.

Study Design and Setting

This study used a descriptive, qualitative design to explore the perceptions of parents on parental participation in the care of hospitalised children. The study was conducted at Queen Elizabeth Central Hospital, a tertiary government referral hospital in southern Malawi. The setting has specialised paediatric services that the researchers wanted to uncover. It was chosen because it is a place where children with complicated conditions are admitted and they stay in the hospital for more than one day.

Study Population Sampling Method

The target population in this study comprised parents who were taking care of children admitted to all sections of the paediatric department in order to gain a broader understanding of their perceptions regarding their participation in the care of their hospitalised children. Purposive sampling was used to recruit participants for this study based on the inclusion criteria. The participants were selected because they were knowledgeable and had experience of the phenomena under study.

Sample Size

Twenty parents were recruited and interviewed. Polit and Beck (2010) indicate that in qualitative studies a sample of 30 or less is adequate, especially when the researcher is using a homogenous sample of participants. Nevertheless, the sample may increase or

decrease depending on data saturation. In this study, data saturation was reached during an interview with the 20th participant.

Inclusion Criteria

The inclusion criteria included parents who had spent more than 48 hours in the hospital with their children, whose children were in a stable condition, and who were able to communicate in Chichewa.

Data Collection Methods

Data were collected using face-to-face in-depth interviews with the aid of a semi-structured interview guide. The interview guide contained demographic information and qualitative information guided by the study objectives. The interview guide sought information on how the caring roles were negotiated between the nurses and parents and how the parents were prepared for their roles. Data were recorded using a voice recorder. Each interview took between 45 to 60 minutes. Data were collected between September and October 2014 by two investigators.

Data Analysis

The demographic data were analysed using descriptive statistics. The qualitative data were analysed using Colaizzi's method (Wirihana et al. 2018). According to Wirihana et al. (2018), Colaizzi's method has seven steps which include reviewing the data, extracting significant statements, spelling out the meaning of each significant statement, organising the formulated meanings into clusters of themes, integrating results into an exhaustive description of the phenomenon under study, extracting fundamental structures and member checking.

Trustworthiness of the Data

The trustworthiness of the data was ensured by adhering to credibility, dependability, confirmability and transferability standards. Additionally, the researcher has provided sufficient descriptive information of the participants and their perceptions to reflect what is happening on the ground.

Ethical Considerations

The researchers ensured that the participants' human rights were respected throughout the research process, i.e. their rights to self-determination, anonymity, privacy, confidentiality and protection from harm. The research protocol was approved by the College of Medicine Research and Ethics Committee (COMREC), which granted the approval number P.04/14/1564. Permission to conduct a study at a paediatric department was obtained from the hospital director. Informed consent was obtained from each participant.

Findings

Demographic Characteristics of Participants

Table 1 shows that most of the parents were female and their ages ranged from 21 to 43 years. Table 1 presents demographic information of the 20 parents who participated in this study.

Table 1: Demographic characteristics of participants

Characteristic	n	% (n/N)
Age in years		
20–24	4	20.00
25–29	6	30.00
30–34	3	15.00
35–39	4	20.00
40–44	<u>3</u>	<u>15.00</u>
Total	20	100.00
Gender		
Male	3	30.00
Female	17	70.00
Total	20	100.00
Level of education		
None	1	5.00
Primary	8	40.00
Secondary education	10	50.00
College education	1	5.00
Total	20	100.00
Relationship to the sick child		
Mother	16	80.00
Father	3	5.00
Aunt	1	5.00
Total	20	100.00
Religion		
Christian	19	95.00
Moslem	1	5.00
Total	20	100.00

Results from the Qualitative Data

The qualitative data were analysed using thematic content analysis (TCA) which was guided by Colaizzi's method (Wirihana et al. 2018). The main themes that emerged were the following: (1) A lack of role negotiation by nurses, (2) inadequate role

preparation for parents, and (3) the perception of parents on the care they provided to their hospitalised children.

Lack of Role Negotiation between Parents and Nurses

The results showed that the majority of the participants ($n=16$) reported that they were not consulted on their caring roles and said that they were given tasks to perform with their children such as encouraging them to eat or take medication. One participant said:

A nurse told me that I am supposed to take care of the child like a parent by doing the activities for the child such as encouraging the child to eat when [he/she] is refusing and encouraging the child to take medication if the child is refusing so that the child should get better. (Participant #3)

These participants said that they did everything for their children because they were not given a choice of which activities to perform. One participant explained the matter in the following way:

We [parents] do everything that we are asked to do because if we refuse sometimes the nurses tell us that it is our child, so we are supposed to take care of him or her ourselves. It's my responsibility to take care of him ... if we refuse doing what they have asked us to do sometimes they stop paying attention to us, they say we are troublesome. (Participant #5)

Inadequate Role Preparation for Parents by Nurses

The majority of the participants ($n=13$) said that they were not prepared for their role and the nurses did not teach them how to carry out various tasks in order to care for their sick children. One participant observed, "we did not discuss anything; what I know is that they just come and ask me how the child is this morning and give us medication [and] that's all" (Participant #7).

Other participants ($n=3$) indicated that it would have been better for them if they were prepared for their roles from admission because they were in a strange environment. A participant made the following comment:

It is the responsibility of the nurses to prepare us caregivers on how we can care for our patients because when they prepare us we know that what we want to do the nurses will be happy with that. If we are taking care of the child on our own ways sometimes it may be possible that we are afraid that maybe what we are doing maybe the doctors may not be happy with. They may shout at us. (Participant #9)

However, there were other participants ($n=7$) who said that they were informed how to carry out various tasks, but this was only done under instruction from nurses. One participant said:

I was told that the shunt that they inserted on the child, I should not let him sleep on that side because the wound has not healed but also, I should protect him well on the wound,

water should not enter. I was also told that I should not put him to sleep on the wound site because if I let him lie on that side [he] may experience pain. When the wound got healed, they also told me to let him lie on that side. They explained how I should do it. They also taught me how to feed the child through the nasogastric tube. (Participant #6)

Perceptions of Parents on the Care They Provided to Their Hospitalised Children

The perceptions of parents regarding the care they provided to their children describe the actual care the parents provided and their views on their participation in this care. Specifically, these views centred around the appropriateness of parents' participation, their satisfaction with the care they gave to their children and their overall impressions of their participation in the care of their hospitalised children.

Basic Care

All participants mentioned that they bathed their children, wiped them, washed clothes for them, cleaned the place where the children were sleeping, and changed them whenever they had soiled themselves. One participant said:

I bath my child, washed his clothes. This is what I normally do at home for him. I am just doing what a mother is supposed to do [for] her child. (Participant #1)

Technical Care

Almost all the participants ($n=19$) mentioned that they were involved in the administration of oral medication. Other tasks included simple wound dressing, collecting urine specimen, feeding children through the nasogastric tube (NGT) and doing passive range of motion exercises with their children. One participant said, "but some of these tasks that they give us are supposed to be done by the nurses" (Participant # 5).

Reasons for Taking up the Caring Roles

Most participants ($n=14$) reported that they were doing the tasks for their hospitalised children because they felt responsible for their child's care. One participant's observation illustrated this:

The child relies on you as a parent like the person who can take care of him. That is why I saw that when the child was sick there was need for me as a parent that I should take part in caring for him. (Participant #9)

Benefits of Parents Participating in the Care of Hospitalised Children

A few participants ($n=4$) indicated that when they participated in the care they understood their child's illness better, although their understanding was not detailed except for those who had asked the healthcare workers (HCWs) for details. One participant said:

I learnt a lot from the nurses about my child's illness since I was able to ask them questions that were answered. This enabled me to understand what was happening to my child when the HCWs were giving treatment to him. (Participant #12)

Some participants ($n=10$) said that their participation ensured that children received comprehensive and individualised care. One participant revealed the following:

The nurses do not do most of the basic things for the children. These things are done mostly by the parent. For example, the child may have diarrhoea, so it is the parent who cleans the child and washes for him or her, the nurses do not clean them. (Participant #15)

Some participants ($n=8$) reported that the parental participation also benefits the nurses. Nurses have a lot of tasks to complete for many patients. One participant asserted that

we help busy nurses who have a lot of tasks to perform. What they could have done we do them, for instance if the child is supposed to give urine specimen the nurses just give us the bottle and we collect the urine ourselves. (Participant #20)

Overall Impression of Parents on Their Participation in the Care of Their Hospitalised Children

Two sub-themes emerged under this theme: the appropriateness of caregivers' participation in the care of hospitalised children and the caregivers' satisfaction with their participation.

Appropriateness of Parents' Participation in the Care of Their Hospitalised Children

The majority of the participants ($n=19$) viewed their participation in the care of their hospitalised children as appropriate. One participant summed it all up and said:

It is proper that I should participate because this is my child. It requires me as the owner who gave birth to this child like the parent to be the first to take part. It is right and proper that the first care should come from me so that other people who are helping should just be helping. I am not feeling any pain when caring for my child and I know that the child is mine. (Participant #12)

Parents' Satisfaction with Their Participation

All participants indicated that they were satisfied with the way in which they were participating in the care of their children. One participant's observations illustrated this:

I am satisfied in the way am participating because I am able to see the change in my child's condition because I am taking part in the care unlike if I was not participating, I could have not seen this change. (Participant #10)

Discussion

The results showed that parents were not consulted by nurses to discuss the activities they were supposed to do whilst in the hospital in terms of the care their children required. The findings also indicate that some were told by nurses that they were supposed to be taking care of their hospitalised children. It was also reported that other parents were told by nurses to observe what their fellow parents were doing to care for their children. These findings are similar to the findings of many studies that found staff took it for granted that parents should participate in the care because they are there with the child (Priddis and Shields 2011, 15). This is contrary to the concept of family-centred care practice of which parental participation is an integral part. The practice of family-centred care requires nurses to negotiate the caring roles with caregivers (Vasli and Salsali 2014, 139). This implies that nurses need to be aware that parents differ in terms of the amount of participation they want to have. It has been documented that parental participation can be controlled by adequate role negotiation and preparation (Fegran and Helseth 2009, 670; Hoffman et al. 2012, 74). However, as reported by participants, nurses in this study did not fully negotiate with parents regarding the level and type of care they need to participate in. A lack of role negotiation between nurses and parents results in nurses placing increasing responsibility on the parents without providing the support that they need (Priddis and Shields 2011, 19). The literature has documented factors that hinder negotiation between nurses and parents (Aein et al. 2009, 226; Ames, Rennick, and Baillargeon 2011, 143). Ames, Rennick, and Baillargeon (2011, 148) reported that nurses do not negotiate with parents because they are busy, lack time, fear increased technical care, face inadequate staffing and lack negotiation and communication skills. This may be true for the nurses in this study because a shortage of staff is a chronic healthcare problem. The implication of not negotiating the care is that parents feel less empowered and powerless to contribute effectively to the care of their child whilst in the hospital. This may compromise the quality of care that the child may receive in the hospital.

The study findings showed that the parents were inadequately prepared for their caregiver roles by nurses. Role preparation involves establishing rapport, discussing caregiving with family members, assessing their level of capability, and teaching family members the tasks through demonstration followed by return demonstration (Fegran and Helseth 2009, 667; Vasli and Salsali 2014, 139). Mackay and Godfrey (2011, 6) found that nurses prepared the parents in order to familiarise and prepare them for their new role as partners in the hospital. This means that parents were given control of the task that they needed to perform on their children, which is contrary to the findings of this study. Some nurses in this study delegated the tasks to parents without preparing them. A few parents said that they were taught only when the nurses wanted to give caregivers tasks to do. This is consistent with the findings of a study by Aein et al. (2009, 221) who found that in Iran, nurses delegated the care to parents without sufficient preparation. Several studies concluded that if parents do not have the necessary

knowledge and skills to perform their work they may unintentionally harm their sick children (Jones et al. 2017, 391). This could be true for caregivers in this study.

The basic care that parents performed included staying with their child, bathing, feeding, changing nappies, cheering the child, taking the child to the see-saw, calming and comforting their child during painful procedures. Earlier studies have demonstrated similar findings (Abdelkader et al. 2013, 358; Aein et al. 2009, 224; Ames, Rennick, and Baillargeon 2011, 147; Haskel et al. 2012, 6669). This may mean that providing basic care to hospitalised children is a universal phenomenon undertaken by parents. Aein et al. (2009, 222) indicated that there is a general agreement and an expectation from most caregivers and parents that they need to continue with their parenting role when in the hospital. Phiri, Kafulafula, and Chorwe-Sungani (2017, 142) reported that registered nurses allowed parents of hospitalised children to attend to basic care while the nurses retained control over technical tasks. It may be concluded that parents are willing to participate but the behaviour of nurses may reduce their willingness. This may explain why some nurses were clinging more to technical care than basic care. The fact that parents were involved in providing technical care to their children does not reflect the values of FCC, but rather workload management. This may also explain why parents in this study indicated that they participated in the provision of care to assist and alleviate the burden of busy nurses. Thus, partnering with parents in providing some technical care at this tertiary hospital may be a way of lessening the workload of nurses.

The study findings showed that the parents were satisfied with the way they were participating in the care of their children. Earlier studies have also reported similar findings (Phiri, Kafulafula, and Chorwe-Sungani 2017; 141; Priddis and Wells 2010, 8; Vasli and Salsali 2014, 142). Mikkelsen and Frederiksen (2011, 1560) reported that caregivers expressed gratitude for the opportunity to remain with the hospitalised child and to take part in the care provided. The findings of the present study confirm the findings of earlier research which concluded that basic care is the main area of PP and presents a continuation of the parenting role from home to hospital and vice versa (Abdelkader et al. 2013, 340; Haskel et al. 2012, 69; Jones et al. 2017, 391). While the researcher agrees with earlier conclusions, the quality of care at this hospital may be questionable considering that parents were not adequately prepared for their role.

Recommendations

Given the findings of this study, the authors recommend the following to parents, nurses, and hospital authorities and indicate areas that need future research to address the issues identified in this study and to make parental participation a reality at hospitals.

For Parents

The study showed that some parents desired to and did participate in tasks involved in technical care. However, they did this without adequate preparation, negotiation and information from nurses regarding the roles they needed to perform. This poses a health

risk to their children as parents are not knowledgeable on the technical performance of nursing-related tasks. There is a need for parents to be empowered and vigilant in order to demand and negotiate with nurses regarding their need to participate. Moreover, nurses, as regulators of care, need to reach an agreement with parents regarding the levels at which they can perform the agreed upon tasks. For parental participation to be effective, there is a need for a mutual partnership between parents and nurses.

For Nurses

The findings of this study reveal that nurses do not negotiate the caring roles with caregivers of hospitalised children. In addition, the nurses did not prepare some of the parents for their caring roles. Therefore, there is a need for nurses at this hospital to prepare and negotiate the caring roles with the parents. This will ensure that the parents are empowered in the course of providing the care; it will enhance effective parental participation and prevent unnecessary errors.

For Hospital Authorities

The findings of this study showed that parents view their participation in childcare as appropriate, important and satisfying. However, gaps exist in the ways parents participate in the care of their hospitalised children at this hospital as nurses do not prepare and negotiate the caring roles with parents of hospitalised children. To enhance effective parental participation, hospital authorities need to develop and implement policies and guidelines on which nurses and parents can base their practice of parental participation in childcare.

For Future Research

From the identified gaps, further studies are needed that focus on nurses' and other healthcare workers' experiences and perceptions of parental participation in the care of hospitalised children. There is a need for intervention studies on the feasibility of implementing parental participation at the hospital as well as studies that focus on factors which contribute to inadequate negotiation between nurses and caregivers regarding the roles the latter are expected to fulfil and inadequate preparation to fulfil these roles.

Limitations of the Study

Nurses' and other healthcare workers' views regarding their experiences with parental participation were not sought. Seeking nurses' and other healthcare workers' views would have enriched the findings and conclusions of this study.

Conclusion

In conclusion, the findings of this study showed that parents view their participation in the care of their hospitalised children as appropriate, important and satisfying. However, gaps exist in the way parents participate in the care of their hospitalised children. This

is because there is inadequate role negotiation with and preparation for parents and inadequate information sharing between nurses and parents. To ensure effective parental participation, nurses need to negotiate the caring roles with the parents so that they are empowered to participate and adequately provide care to their hospitalised children.

References

- Abdelkader, R. H., D. H. Arabiat, L. A. Abushaiha, and I. Qadri. 2013. "Mothers' Experience of Caring for Their Hospitalized Child in Jordan's Hospitals." *Life Science Journal* 10 (4): 336–42.
- Abdelkader, R. H., I. Khalaf, S. Kridli, D. Arabiat, and I. Alrimawi. 2016. "Parents Involvement in Child's Care in an Arab Pediatric Setting." *Health Science Journal* 4 (10). Accessed April 17, 2020. <https://www.hsj.gr/medicine/parents-involvement-in-childs-care-in-an-arab-pediatric-setting.php?aid=9879>.
- Abdulbaki, M. A., Y. A. E. Gaafar, O. G. Waziry. 2011. "Maternal versus Pediatric Nurses' Attitudes regarding Mothers' Participation in the Care of Their Hospitalized Children." *Journal of American Science* 7 (9): 316–27.
- Aein, F., F. Alhani, E. Mohammadi, and A. Kazemnejad. 2009. "Parental Participation and Mismanagement: A Qualitative Study of Child Care in Iran." *Nursing and Health Sciences* 11 (3): 221–27. <https://doi.org/10.1111/j.1442-2018.2009.00450.x>.
- Al Momani, M. M. 2011. "Mothers' Satisfaction towards Pediatric Nursing Care: Family Centered Care Initiative." *Middle East Journal of Nursing* 5 (5): 28–34. <https://doi.org/10.5742/MEJN.2011.55106>.
- Ames, K. E., J. E. Rennick, and S. Baillargeon. 2011. "A Qualitative Interpretive Study Exploring Parents' Perception of the Parental Role in the Paediatric Intensive Care Unit." *Intensive and Critical Care Nursing* 27 (3): 143–50. <https://doi.org/10.1016/j.iccn.2011.03.004>.
- Coyne, I. 2015. "Families and Health-Care Professionals' Perspectives and Expectations of Family-Centred Care: Hidden Expectations and Unclear Roles." *Health Expectations* 18 (5): 796–808. <https://doi.org/10.1111/hex.12104>.
- Fegran, L., and S. Helseth. 2009. "The Parent-Nurse Relationship in the Neonatal Intensive Care Unit Context—Closeness and Emotional Involvement." *Scandinavian Journal of Caring Sciences* 23 (4): 667–73. <https://doi.org/10.1111/j.1471-6712.2008.00659.x>.
- Harrison, T. M. 2010. "Family-Centered Pediatric Nursing: State of the Science." *Journal of Pediatric Nursing* 25 (5): 335–43. <https://doi.org/10.1016/j.pedn.2009.01.006>.
- Haskel, H., M. E. Mannix, J. T. James, and D. Mayer. 2012. "Parents and Families as Partners in the Care of the Pediatric Cardiology Patients." *Progress in Pediatric Cardiology* 33 (1): 67–72. <https://doi.org/10.1016/j.ppedcard.2011.12.011>.

- Hoffman, M., I. Mofolo, C. Salima, I. Hoffman, S. Zadrozny, F. Martinson, and C. Van Der Horst. 2012. "Utilisation of Family Members to Provide Hospital Care in Malawi: The Role of Hospital Guardians." *Malawi Medical Journal* 24 (4): 74–78.
- IPFCC (Institute for Patient- and Family-Centered Care). 2013. "Core Concepts of Family Centred Care." Accessed September 12, 2014. <http://www.ipfcc.org/pdf/CoreConcepts.pdf>.
- Jolley, J., and L. Shields. 2009. "The Evolution of Family-Centered Care." *Journal of Pediatric Nursing* 24 (2): 164–70. <https://doi.org/10.1016/j.pedn.2008.03.010>.
- Jones, J., A. S. Nowacki, A. Greene, C. Traul, and J. Goldfarb. 2017. "Investigating Parent Needs, Participation, and Psychological Distress in the Children's Hospital." *Hospital Pediatrics* 7 (7): 385–94. <https://doi.org/10.1542/hpeds.2016-0175>.
- Mackay, L., and D. Godfrey. 2011. "Exploring Family-Centred Care among Pediatric Oncology Nurses." *Journal of Pediatric Oncology Nursing* 28 (1): 43–52. <https://doi.org/10.1177/1043454210377179>.
- Mikkelsen, G., and K. Frederiksen. 2011. "Family-Centred Care of Children in Hospital—A Concept Analysis." *Journal of Advanced Nursing* 67 (5): 1152–62. <https://doi.org/10.1111/j.1365-2648.2010.05574.x>.
- Phiri, P. G. M. C., U. Kafulafula, and G. Chorwe-Sungani. 2017. "Registered Nurses' Experiences Pertaining to Family Involvement in the Care of Hospitalised Children at a Tertiary Government Hospital in Malawi." *Africa Journal of Nursing and Midwifery* 19 (1): 131–43. <https://doi.org/10.25159/2520-5293/910>.
- Polit, D., and C. T. Beck. 2010. *Essentials of Nursing Research: Appraisal Evidence for Nursing Practice*. 7th ed. Philadelphia, PA: Lippincott Williams and Wilkins.
- Priddis, L., and L. Shields. 2011. "Interactions between Parents and Staff of Hospitalised Children." *Paediatric Nursing* 23 (2): 14–20. <https://doi.org/10.7748/paed2011.03.23.2.14.c8373>.
- Priddis, L. E., and G. Wells. 2010. "An Innovative Group Approach to Working with Families to Improve Parent/Infant Relationships within a Community Setting." *Journal of Neonatal, Paediatric and Child Health Nursing* 13 (3): 20–24.
- Vasli, P., and M. Salsali. 2014. "Parents' Participation in Taking Care of Hospitalized Children: A Concept Analysis with Hybrid Model." *Iranian Journal of Nursing and Midwifery Research* 19 (2): 139–44.
- Wirihana, L., A. Welch, M. Williamson, M. Christensen, S. Bakon, and J. Craft. 2018. "Using Colaizzi's Method of Data Analysis to Explore the Experiences of Nurse Academics Teaching on Satellite Campuses." *Nurse Researcher* 25 (4): 30–34. <https://doi.org/10.7748/nr.2018.e1516>.

Zhou, H., L. Shields, R. Watts, M. Taylor, A. Munns, and I. Ngune. 2012. "Family-Centred Care for Hospitalized Children Aged 0–12 Years: A Systematic Review of Qualitative Studies." *JBI Database of Systematic Reviews and Implementation Reports* 10 (57): 3917–935. <https://doi.org/10.11124/01938924-201210570-00006>.