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# Nurses' Perceptions of Parents Staying during Chronically Ill Child's Hospitalization: Learning to Speak the Same Language

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Nurses' Perceptions of Parents Staying during Chronically Ill Child's Hospitalization:

Learning to Speak the Same Language

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A project based upon an independent investigation,  
Submitted in partial fulfillment of the requirements  
for the degree of Bachelors of Arts in Social Work.

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## Abstract

Since parents and nurses are at the forefront of a hospitalized child's care, it is crucial to understand the views of parents and nurses to provide the best care for the patient. Parental views have been examined by previous research; thus, this qualitative research study assesses nurses' perceptions concerning the parental role during a child's hospitalization. Assessing where nurses' place parents in the medical world will help the overall care of the patient. The results of the semi-structured interviews of two nurses corresponds with the hypothesis that nurses' view parents as integral to the care of the patient, even if that view creates logistical issues for the nurses. Nurses' perspectives can inform the pediatric healthcare system to appreciate the vital role of parents in providing the best patient care. Further research can expand on this important area by interviewing different pediatric nurse specialties to establish more comprehensive viewpoints.

*Keywords:* hospital, child, nurse-parent relationship, nurses' scope of work, parental participation

The current mixed methods study will assess nurses' perceptions of parents remaining with their chronically ill child/children during a hospitalization. Addressing recommendations from previous research pertaining to the current topic, this study will attempt to understand health care providers' perspective in order to provide appropriate best practice strategies to implement for integrating parental care and knowledge with the care and knowledge offered by health care professionals during a hospital stay (Balling & McCubbin, 2001; Callery, 1997; Power & Franck, 2008; Shields, Kristensson-Hallström, & O'Callaghan, 2003; The Welfare of Children in Hospital, 1959; Vasli & Salsali, 2014; Ygge & Arnetz, 2004). It will also address the need to understand nurses' motivations and how that affects the type of care that parents of hospitalized chronically ill children receive and perceive.

In order to properly assess and understand the results of this study, certain criteria will be implemented for key stakeholders of the study. Nurses will include not only registered nurses (RNs) but also Certified Nursing Assistants (CNAs), and Licensed Practitioner Nurses (LPNs). Children will be defined from the age range of eight years old to seventeen, and chronically ill will be defined as an ongoing, frequent or recurrent medical condition that effects the child's life to the point at which medical hospitalization is required. The term parents will be used to define the guardians of the child that are caretakers outside of the medical community and are part of the child's family system. For the purposes of this research study, the facilities will be hospitals that have a pediatric unit, or specialize in pediatric care and health care professionals will include all of the staff that can interact, on a medical level, with the parents and child. This would include personnel such as physicians, therapists, and hospital administration.

Since social workers have been a part of the hospital system since at least the 20<sup>th</sup> century (The Welfare of Children in Hospital, 1959), they have a vested interest in providing the best

care possible. Additionally, as a profession with a focus on integrating needs, this study will integrate the needs of nurses, with the needs of parents, to ultimately provide the best outcomes for the 10% to 30% of chronically ill children in the American population (Berge & Holm, 2007, p. 123). Addressing and advocating for the needs of vulnerable populations is inherent in the values and ethics that the National Association of Social Work upholds (National Association of Social Workers, 2008, Preamble). By addressing the communication and logistical flaws within the system and interpersonal relationships of hospitals and the families they serve, this study is starting to create practical resources for this vulnerable population.

The study begins with an examination of the current literature on the importance of the parents staying during their child's hospital stay, as well as the parents' perceptions of their own needs, and how physicians acknowledge and address those needs during their child's stay. A qualitative study will then analyze nurses' perceptions of parents staying with their chronically ill child during a hospitalization in order to ascertain what limits or creates barriers to providing the best quality of care for the child. This study will further attempt to take the information obtained from the semi-structured interviews, and integrate it with the knowledge acquired from the review of the literature in order to help assess best practices and integration of the needs of both parents and nurses to create a sample model in the pediatric hospital arena.

### **Literature Review**

The idea of pediatric hospitals, and hospitals that have a pediatric ward were relatively non-existent in the 19<sup>th</sup> century. Instead, there were facilities in which children could receive care, but it was sustained and operated through charitable funds, and was considered completely different from an adult hospital (Davies, 1997). With the change in how child medical care was administered, there was a slow progression to the change in hospital policies. Specifically, the

idea and importance of integrating family, and especially parents, into the hospital stay of their ill child was first publically acknowledged through a British subcommittee addressing the best interests of children. Now known as the Platt Report, *The Welfare of Children in Hospital* (1959) addresses changing expectations and needs in pediatric hospitalizations. The *Welfare of Children in Hospital* (1959) article cites that “[a]ccommodations should be made available wherever possible for the mothers of infants and toddlers, preferably with the mother sleeping in the same room as her child...” (p. 166). This starting point placed emphasis on allowing parents to physically be present in the hospital-like settings, as well as the communication between physicians and parents, parental understanding of their child’s care plan, as well as discharge plans and protocols (*The Welfare of Children in Hospital*, 1959). Further, Ygge and Arnetz (2004) found that “The Platt Report was the result of research by pediatricians who demonstrated that a child’s separation from its parents could have negative effects on the child’s character and mental development” (p. 217).

After more than fifty years since the Platt Report was published, the same issues of parental inclusion, participation, and allowance to stay with their child during hospitalization are being assessed. In order to understand the importance of parental inclusion, one must first review the effects that parental involvement have on a child’s healthcare, as well as on the parents own personal well-being.

### **The Need for Parental Involvement**

**Parental needs.** Parents of children who are chronically ill have certain needs that need to be attended to and acknowledged. Lourdes, Nunes, and Noemia (2012) found that “the disease is an episode in one’s life and his family that causes the breakdown of references, forcing them to adapt to the new reality...” (Translated from Spanish, *Changes in Family Life*, para. 7). Thus,

the chronic illness not only affects the child, but the family system as a whole (Translated from Spanish Lourdes, Nunes, & Noemia, 2012, Changes in Family Life, para. 4). Chronically ill children are also more reliant on their parents, especially when they are younger, since they are unable to advocate for themselves in some cases. Furthermore, parents also have the logistical role of being the legal guardian of the child, and thus they decide all aspects of the child's care (Ygge & Arnetz, 2004, p. 217).

***knowledge.*** In order for parents to advocate for their child, parents need to feel a sense of empowerment and strength when entering into the medical community. These feelings of empowerment and strength, however, are often interrupted by the fear of the unknown, described as ambiguity (Berge & Holm, 2007, p. 124). Ambiguity, more often than the child's illness, causes anxiety, depression, fear and guilt in parents that can affect a parents' level of interaction as well as their overall state of health (Balling & McCubbin, 2001; Berge & Holm, 2007; Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009; Power & Franck, 2008; Ygge & Arnetz, 2004). In order to reduce this ambiguity that parents face, research has found that by providing detailed information on the chronic illness the parents' child suffers from, along with treatment methods, continued contact with medial caregivers, staying up to date with new research, as well as understanding how and why procedures are being done, are extremely important steps in easing parental unease and ambiguity of the situation at hand (Balling & McCubbin, 2001; Berge & Holm, 2007; Lourdes, Nunes, & Noemia, 2012; Power & Franck, 2008; Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009; The Welfare of Children in Hospital, 1959; Vasli & Salsali, 2014; Ygge & Arnetz, 2004).

***Parent-child relationship.*** Understanding the chronic illness a parent's child suffers from is extremely important because of the relationship that parents and children have with one

another. Parents and children have a unique bond, which makes parental involvement so important to provide the best care to the child. Parents are with their children more than nurses and any other health care providers, thus, parents have a view of the child's day-to-day life and health that health care providers do not have, which parents see as a key contribution that they can provide to their child's care (Power & Franck, 2008, p. 637). Some parents go so far as to say that they can care for their children better than health care professionals do in the hospital (Balling & McCubbin, 2001, p. 115). From an emotional standpoint, "[p]arents give the child emotional support and act as a bridge between the child and hospital staff" (Ygge & Arnetz, 2004, p. 217). This decreases the stress of the child, lessening the overall stress on the child's body. This knowledge of one's child brings so much valuable information to health care providers, however, the intense bond between parent and child can make hospitalization difficult, as "[p]arents experience changes in their parental role when their child is cared for by health care professionals..." (Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009, p.121). This needs to be addressed and acknowledged in the care plan in order to provide the care and concern that parents need during this difficult time.

***Parental participation.*** Since it is clear that parents want to be involved in their child's healthcare plan during a hospitalization, the next question is how involved do parents want to be. There is conflicting evidence on the level of involvement that parent's desire. While some parents want to do or participate in any type of medical procedure or care for their child, others are confronted with "...feeling undervalued...pressured to participate and being uncertain of participatory expectations..." (Power & Franck, 2008, p. 623). Furthermore, some parents feel that by needing "...support...[parents felt it] was inappropriate...to be considered as 'patients' when it was the child who was ill..." (Callery, 1997, p. 993). These complicated feelings need to



be acknowledged, combated, and communicated with the child's health care team, especially nurses, who are at the forefront of the healthcare system.

### **Parents and Nurses.**

**Parents' desires.** Parents ultimately want to have open and honest communication with the medical community during their chronically ill child's hospitalization. This open communication will allow parents to ask the questions that might make them feel exposed or uncertain. It will also help establish new boundaries, since, as was pointed out previously, roles change from before a hospitalization and during a hospitalization. By talking about what is expected of the parents, and what the nurses aim to do, the parents will be informed and will be able to feel that they are a part of the conversation of the care that their child is receiving, rather than a problem (Vasli & Salsali, 2014; Ygge & Arnetz, 2004). Having boundaries can also lead to a hospitalization routine, where the staff and parents decide what tasks the parents are comfortable and willing to do for the child and what the nurses and other health care providers will do for the child during his or her hospitalization. This gives parents purpose, and also empowers them to "...take charge of the situation and then hold on to their sense of power" (Ygge & Arnetz, 2004, p. 218).

Since parents are so interconnected to their children, nurses need to not only provide informational support, but also emotional support by "...listening, exhibiting caring behaviors[,] and being concerning in ways that help parents cope with the child's illness and other aspects of their lives that are impacted by the illness" (Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009, p. 122). This emotional support can be continued through giving praise to parents without being condescending. This type of support will build a trusting relationship and knowledge the difficulty that parents with chronically ill children live with everyday.

From this open communication, parents can also build more trust in the health care providers caring for their ill child, and might allow themselves the necessary respite that some parents said they wished for during hospitalizations (Power & Franck, 2008, p. 639). This can then be seen in the child, who looks towards their parents for reassurance and how to feel in certain situations, especially when they are young and in a vulnerable state. The topics and decisions made from open communication will improve the overall quality of care that the child receives during a stay (Vasli & Salsali, 2014, p. 139). As one mother said in a qualitative study by Ygge and Arnetz (2004):

You do not want to question the hospital staff in front of your child, it is too much of a burden for the child to bear, that there could be a conflict between hospital staff and parents. We must all speak the same language to the child, it is for the child's best. The child must be able to trust us. (p. 220)

**Nurses' conundrums.** Most nurses believe that there is a vital role for parents when a chronically ill child is hospitalized and see the importance of understanding and working within the family structure, within the context of the best interest of the child (Callery, 1997). However, "...it was not clear what was the nature and extent of the aspect of...[the parents'] work" (Callery, 1997, p. 994). Nurses have trouble balancing the need to include the parents and provide them information while addressing the rest of their caseload, as well as knowing how much responsibility to give the parents, while also thinking about the possible repercussion for anything that goes wrong under the parent's watch. The fear of litigation was brought up in the 1959 Platt Report, and concluded, "...the ward sister must not be made to feel that she is personally responsible for all accidents. This leads to an atmosphere of fear and disapproval and to a lack of free and open discussion on the causes of accidents" (p. 168). Although this is the

ideal viewpoint, our current society is litigious in nature and nurses are stuck between taking the risk for the best interest of the patient, or losing the trust and open communication from the parent.

Nurses are also inundated with a high number of patients who often have high needs. This causes parents to view nurses as being too busy and understaffed to help, which in one study led to an "...unspoken assumption that they[, the nurses] would be unavailable to assist in their child's care because nurses were often too busy" (Ygge & Arnetz, p. 115). This view of "busy nurses" may be true, but the best interests of the patients must be taken into account. Nurses have also avoided parents sometimes due to the fact that they did not have the answers for the parents (Ygge & Arnetz, 2004). Although the nurses might be trying to avoid inflicting pain onto the parents, avoiding the parents is creating a bigger problem: lack of trust. It would be better if the nurses were honest and truthful, even if the answer is extremely difficult.

### **Implications**

From the literature compiled, one can see the discrepancy between knowledge concerning the views and understandings of parents, and those of nurses. By understanding the perceptions of nurses, the literature will be well rounded in the sense of addressing the different needs of those in the forefront of caring for chronically ill children. With the new data found from the current research study, potential best practices can be created to accommodate both the parents and the nurses in the pediatric ward. Further, by understanding nurses' perceptions, parents can be informed and nurses can become more aware of their habits in order to provide the best care for their primary patient, the child, as well as the secondary patient, the parents. Understanding nurses' perceptions can also help social workers who are working in pediatric units sympathize for both parents and nurses, allowing the social worker to look towards the strengths of each

party to create a realistic solution for parental involvement in pediatric care. Primary questions will include comparing the literature concerning nurses' perceptions to the semi-structured interviews from this study. Inquiring whether or not nurses' perceptions affect the quality of care a pediatric patient received. Whether or not nurses believe that by working with parents, the child's overall health will increase. What do nurses find difficult when working with parents of chronically ill children? How do nurses perceive parents staying with their chronically ill child during a hospital stay? What obstacles do nurses encounter when parents stay overnight? Are there logistical issues that nurses encounter when a parent has the desire to stay with their ill child, and how does this impede parents and nurses working together? All of these questions will create a general framework that can assist in future research and possible changes to improve the communication and overall stay that the family with a chronically ill child has during a hospitalization.

### **Methodology**

This qualitative research study assessed nurses' views and perceptions of parents staying with their chronically ill children during a hospital by interviewing pediatric nurses. A qualitative method was chosen in order to ascertain perceptions that would be more evident in a conversation with questions, than with other methodologies, such as surveys. Also, since perception and stories are intertwined, being that stories are expressions of experiences through the person's point of view (Sandelowski, 1991). Providence College's Institutional Review Board approved this study, including the evidence collecting method of semi-structures qualitative interviews.

### **Participants**

Pediatric nurses were found using a sample of convenience with the snowball method, starting with the researcher's community contacts and then finding one pediatric nurse who was willing to participate as an individual, rather than as an extension of their place of work. This allowed for a more comprehensive analysis based on pediatric nurses, rather than pediatric nurses of a certain hospital or organization. The researcher then used their contacts to find other pediatric nurses who were willing and available to participate.

Two pediatric nurses were interviewed through in this qualitative study. Both subjects identified as non-Hispanic or Latina Caucasian females. Both were 52 years old in age. Subject 1 was a PICU (pediatric intensive care unit) nurse for 13 years, out of approximately 18 years of being a nurse. Subject 2 has been a pediatric nurse her entire career, which spans 28 years. Currently Subject 2 is in her sixteenth year as a pediatric emergency department nurse. Subject 2 has also been a pediatric floor nurse, as well as a school nurse.

This convenience sample does have some potential biases, such as under-representation, and low generalizability, as well as the potential for social desirability bias. Furthermore, the limitations of generalizability are greater due to the small amount of subjects that were interviewed. However, snowball sampling is the most convenient and fiscally manageable sampling method, and biases are accounted for as limitations to the study. Future research can address the potential biases and counteract any possible biases found from this study. Additionally, the caliber of information, as well as the honesty given within these interviews provides a foundational beginning for this topic of research.

### **Materials and Procedure**

Once participants were found, the researcher structured the interview by creating an atmosphere that was private and yet comfortable in order to facilitate comfortability and honesty

in answers. This atmosphere was the same in both interviews to continue to diminish the probability of discrepancies due to environmental changes. Then the pediatric nurses were given a consent form approved by the IRB to sign (Appendix A). The consent form indicated that the participants knew that they were involved in a research study, their identify would be de-identified, they were aware and consented to being recorded for the purposes of quality for the interview (contact researcher for transcription of the interviews). The subjects had received a list of resources that were available in order to uphold the ethical need to prevent and counteract any harm that the interview may have caused the participants, however slight. Once the consent form was signed, the researcher began recording, reiterated the main points of the consent form.

The researcher posed the questions to the participants in a semi-scripted order to allow for honest answers without having the interview method skewing the data collected (Appendix B). The interviewer remained neutral when asking questions and listening to answers in order to preempt biases. The interviewer did not establish a time limit, as to allow for the most comprehensive information and to make the participants feel more comfortable. The researcher concluded the interview after the questions were answered and thanked the participant for his or her time and information. The researcher reiterated resources that were available to the participants in order to uphold ethical responsibilities to prevent or help reduce any potential harms.

Once all the interviews were conducted, the researcher transcribed the recordings by hand. The researcher listened to the recording again, once the transcription was complete, in order to provide the most accurate account of the interaction as possible. The researcher then assessed the transcriptions to find trends or patterns in the participants' responses.

## **Main Analyses**

The researcher analyzed the transcriptions for potential trends between the two subjects, such as common statements made by subjects, common feelings, and common views of the situation presented in the questions during the interview (Appendix B). Trends were compared to the hypotheses that pediatric nurses would want parents to stay emotionally and pediatric nurses would cite logistical obstacles in accommodating parental involvement. These trends will be expressed and expounded upon in the next sections in relation to this hypothesis. The researcher accumulated the trends into concrete evidence in order to find nurses' overall perception of parents staying with their chronically ill child during a hospital stay. Trends were separated according to categorical variables, and from such trends, implications and recommendations were made in order to begin the research concerning nurses' perceptions in order to provide the best care to pediatric patients overall.

### **Findings**

This study aimed to examine nurses' perceptions of parents staying with their chronically ill child during a hospitalization in order to understand different perspectives of those working with children so as to provide the best practices in child healthcare in a hospital setting.

### **Demographics**

As stated in the methodology section, two 52-year-old subjects were interviewed. Both subjects have worked in pediatrics, Subject 1 in PICU, Subject 2 in school settings, pediatric hospital floors, as well as the pediatric emergency department. With Subject 1 being in pediatrics for 13 years, and Subject 2 working in pediatrics for 28 years, these two subjects provide a well-rounded combination of experience and skills, allowing the researcher to understand different aspects of pediatric care, and the changes that occur depending upon which type of care a pediatric nurse pursues.

### **Nurses' Sense of Duty**

Subject 1 and Subject 2 described their daily routine and duties differently. Subject 2 focused on the specific tasks, which included assessing the level of care needed for the patient, in other words triaging the patient, to after triage where the nurses assisted in conducting trauma level care, from Level 1, where the child needs immediate care, to Level 4, where the child could have gone to a pediatrician instead of the emergency department. If an emergency room pediatric nurse isn't in the triage position, he or she will be working with patients who have already been checked in, administering vital signs to the child, working with the physicians to get blood draws, or make sure the different tests are taken to help the child as quickly and thoroughly as possible.

Subject 1, on the other hand, focused on the abstract and emotional aspects of care throughout the interview, by describing her job as all encompassing. Subject 1 stated, "...you learn a lot, saw a lot of [pause] death and suffering..." and explained that as a PICU nurse you are

...everything...you are there for them respiratory wise if they are on a ventilator... but you're their head to toe, you're their everything for them. So whether it is eating or getting fed through whatever way they are getting fed, every aspect of care...plus...meetings with pharmacy, with Social Work, with psych, with doctors, plus the family around. So it is very, very intense and every aspect of that child's physical and emotional...wellbeing, you're responsible [for and] to be that advocate for he or she.

Both subjects found that it is not only important to be there for the patient through the medical aspects, but through the emotional aspects as well. By looking at the patient as



more than their medical issues, and instead as a human being with feelings and fears, attached to a family system that will impact how the child could react, allows these nurses to complete their job to the best of their ability.

### **Nurses' Personal Perceptions of Parental Involvement**

Subject 1 and 2 both believe that having parents involved is critical to the success of the child's health. Subject 2 said that as a pediatric nurse, you are "...working with the whole family, not just the child, [but also] the parents and give the best you can in care."

Subject 1 expressed not only a desire to have parental involvement in her patient's care, but deemed it an obvious aspect of treatment. Subject 1 reported, "...I think it is better in every way..." for parents to be there "...even if it doesn't end well...we are very honest with them, we don't keep secrets from them. ...Anytime they want to talk to somebody...we go out of our way to make sure that they are able to get their questions answered." Furthermore, Subject 1 posed that not only did they want parents to be present, the nurses "...all had a positive experience with the families and encouraged it..." In addition to parents, the PICU floor, according to Subject 1 stated that parents "...at least where I work they were a part of every single day, they were part of every decision." Parents' involvement was "...important to us [the nurses]."

Subject 2 echoed this view, also examining what the parent's point of view could be, stating

As a nurse, you have to remember, I have always had healthy children, which is great, but I have also seen what happens when you don't have these procedures done, so you have to keep in mind that these parents have always had a healthy child...

With this view, Subject 2 continues that being in the hospital at all is "...tough for them, and tough for the child." Thankfully, Subject 2 experiences less push back from parents who are in a hospital setting, compared to other nursing jobs outside of the hospital setting.

Subject 2 and Subject 1 also examined the difference between chronically ill children's parents, and the children that are acutely ill. While acutely ill children and parents might be terrified of a lifesaving IV, chronically ill patients and families have adapted. Both Subjects express a type of teamwork that occurs between the parents and the nurses. Furthermore, the roles aren't as typical. As Subject 2 states that the chronically ill or children with special needs have different parents compared to those without ongoing medical conditions. These parents, Subject 2 finds, can be overprotective, but know their child's needs and medical history better than anyone else. Subject 2 finds this helpful because "...they know what works best...[and helps] especially for communication." More than that, the parents of chronically ill children are "...more relaxed because they know the procedures..." compared to parents who bring their child in for the first time. It is an entirely new world for parents and children who do not have a chronic illness. Each family system needs to be treated differently because they are coming from different life experiences.

These two Subjects were adamant that by involving the parents, not only will the child's care become better, but also the overall experience will be more beneficial for all involved.

### **Nurses' View of Child's Benefit or Hindrance with Parent Present**

Subject 1 not only wanted parents to be involved, but also cited them as integral to the child's health, as she stated "...especially the little ones, they cry for them [the parents], they are like, 'oh, when is she coming back.' " Subject 1 also explained that parents, "...if they asked, 'what can we do, what can we not do?' we [the nurses] would accommodate to the point where, 'what do you want?' " They would allow the parents to be in the same bed as the patient or hold the patient. Subject 1 viewed this as an important part of being a PICU nurse.

We really wanted them, the child, and the parents, to feel more like 'I'm here with my mother' so whatever we could do to make it less of a hospital and more of them feeling comfortable with their mother there, so...as much as physically could be done, we encourage that.

Subject 2 finds the same benefits in having a parent present. The protocol in the emergency department encourages the parent(s) to "...be with their child all of the time, even in the trauma room...we like to...have the parent right with them, because with the children it calms them down a lot and it really gives them support." Subject 2 stated that parents will tell the nurses 'do what you got to do' "...and they will hug them while you are trying to do the IV and they are really supportive." Other instances of parental support including playing with the child's hair, distracting them by talking to them, reading them a book, or singing. Subject 2 continues "[t]hey'll just reassure them that 'it's ok, it'll be over soon, this will help you get better' so it gives the child a sense of comfort and security." This isn't something that nurses, who are strangers, cannot provide in the same way a mother or parental figure can. It allows the nurse to do his or her job, while still remaining humane and understanding that what they nurses do can be scary and uncomfortable.

Subject 2 examined parent positive presence in another aspect other than emotional, but viewing the parent as another safety measure. The parent can provide "...another set of eyes if we can't see them, especially...with the new building..." where it is more difficult to see all of the patients.

Parents can also be difficult to work with when their child is hospitalized. With acute patients, as Subject 2 accounted for, they are in an entirely new world and even the fact of being in a hospital at all can be too much for a parent in some cases. Subject 2 explained, "some parents...[aren't able to] give them [their children] support, and it can cause a lot of difficulties." Subject 2 recounted an instance where a mother assured Subject 2 that she wouldn't be able to get the child to take the medication, and then was shocked when the child did. There are instances that Subject 2 described where parents aren't able to be the support that the child needs.

...There are some cultures that are extremely emotional, and we will say to them, or even younger parents, 'you know it is ok if you want to take a walk while we do this and you can come back and hug them' and they jump on that, and that's good because them being in the room crying [isn't going to help] and you don't want them to drop in the middle of a procedure.

Subject 2 was definitive in that the amount of parents that are helpful versus hindering is about even. This does not make the half that cannot watch their child in pain "bad parents," it makes them human, and nurses like Subject 2 use their instincts and interactions to gauge what would be best for the family unit overall.

Subject 1 has experienced less resistant or hindering parents during her career as a PICU nurse. However, Subject 1 recounted a severe instance where a small child's life

was on the line because the mother was not able to listen to what Subject 1 had instructed and explained. In this one case, Subject 1 had to intercede against this “obstructive” parent for the safety and overall health of the child. Although it was a very rare occurrence in the PICU, compared to a half and half experience in the emergency department, neither subject blamed these parents or viewed them negatively. Instead, they focused on the overall wellbeing of the child and looked at the parent with understanding and empathy. As Subject 1 said her “job was to be her mother” which is not an easy task, especially when your child’s life is in the balance.

After listening to both of these stories, Subject 1 and 2 still maintained throughout their interviews that parents were always more of a help than a hindrance, and if they were a hindrance, it was an obstacle to work through on a case by case basis, which can range from telling the parent to take a breath and get some fresh air, or calling security and stepping in for the betterment of the child.

### **Nurses’ View of Parents as Secondary Patients**

When Subject 1 was asked about parental involvement in the form of education and emotional comfort Subject 1 cited having many discussions with parents with chronic asthmatic children whose parents smoked or talking to parents after a physician told the parent that the child was not going to survive unfortunately. Subject 1 explained that she would see some parents as secondary patients and explained, “...it was frustrating, but you talk to them the same, like I would never talk down to anyone because they smoked of course...[or because they] were limited educationally or intellectually.” Instead, Subject 1 used “...whatever resources we had for them, whether it was financial or if they needed nurses at home, or needed teaching,

additional teaching, there are always services that we provide, we would try to think of ways to provide ...and there are always numbers to call.”

Subject 2 also described a great deal of educational discussions with parents and described education as “...the most important thing.” Subject 2 explained “...we need to tell them at length what their child has, how this can actually help their child get better, and sometimes we have to tell them the outcome if they don’t let us do this kind of care. They certainly can refuse it...[but usually] by the fourth person...they kind of understand...” Subject 2 explained further that “...by explaining everything to the parent...[they can] get over it and understand it to get through the procedure or just the care of being in the hospital.”

Both Subject 1 and 2 agreed that parents were secondary clients in most cases. Subject 2 exemplified this during the interview as she explained “...you feel like you are treating the child and the parent at the same time, you are treating both of them so you do our best to keep the parent comforted and then the child will be comforted.” This shows the intense bond between parents and child. By relaxing and calming the parent, Subject 2 found that the child would be calmer as well. This connection is imperative to understand and account for when working in pediatrics.

### **Nurses’ Logistical Problems**

When asked about the physical space that Subject 1 worked in, she replied “...we used to always joke about obviously no one consulted a nurse when figuring out the configuration of these rooms...but it was already when I came in after the fact, it didn’t matter, they didn’t ask any nursing.” Subject 1 said that she did wish that nurses were involved in the process but “...that’s just all money we have no control over.” Subject 2 echoed the need for more room and

lack of space. Instead of the rooms being too small, Subject 2 has found that her place of employment is currently having difficulty with placements for patients with psychiatric issues. Due to the fact that the hospital does not have a room, the psychiatric patients waiting for a room or a bed in the ER have to be in a room together with a guard and without their parents, since parents of other children cannot see each other. Subject 2 explained "...they have to undress and put the paper scrubs on and it's really, it's kind of really sad, but we want them safe, we need them safe and we need to explain that."

Another physical boundary is the new layout of the hospital. Although the new rooms allow for more space, Subject 2 describes the difficulty it causes when she needs to check on patients and they are spread out so much that it takes so much longer. With the new construction, which, unlike the PICU unit, head nurses were consulted, Subject 2 is hopeful that it will be easier and more user friendly to nurses and patients.

In addition to the physical lack of space, the layout has also affected the flow of care in Subject 2's work. Due to changes in the hospital's emergency department, the ability to keep medical information confidential and HIPAA upheld is difficult. People are checking in at the emergency department where there is little privacy to explain what the reason for the visit is. This can be extremely difficult in any case, but especially in psychiatric cases. Subject 2 expressed being frustrated and uncomfortable with the lack of privacy, even when calling names.

These difference logistical issues make patient interactions strained. In an environment, both the emergency room and the PICU, where lives are constantly at stake, the need for a fluid and confidential layout for a hospital is needed.

### **Nurses' Boundaries**

Subject 1 had a difficult time answering questions about how to keep her personal boundaries and professional boundaries when treating children. This relates to Berge and Holm's (2007) research on boundary ambiguity. However, where Berge and Holm (2007) discussed this occurrence in the context of it pertaining to parents, Subject 1, as a nurse, found this difficult with a negative experience that she encountered during her time in the PICU. The parent was a NICU, neonatal intensive care unit, nurse and her daughter was in the PICU. After explaining that the child needed to be restrained in order to prevent the child from removing her breathing tube, which would be life-threatening, the mother would not listen and eventually the charge nurse and security had to be called to address the situation. This incident, although extremely rare, according to Subject 1, shows that there is boundary ambiguity with parents and by having seasoned nurses, who understand and care, the situation can be handled and the child was kept safe by the staff in the PICU.

### **End of Life**

Both subjects discussed the taboo subject of what occurs after a child passes. Subject 1 recounted a moving event in which everyone available tried to save a little boy, but after two hours of CPR, the boy had passed. Even in the ultimate moment of sadness, Subject 1 shared that the family came to each staff member, and thanked him or her, by name, for doing everything that they could do for their son. The care and compassion did not end when this young boy's life did, but instead, the nurses supported the parents and the parents were grateful for the nurses.

Subject 2 explained the protocol for end of life in the emergency department as well. Once the child has been declared deceased. The family is brought into a private room, the child is cleaned up and presented as respectfully as possible, and the family has the chance to see the child. The nurses make sure that there are chairs and tissues and food for blood sugar issues in



order to help in any way. The nurses are there, Subject 2 explains that they see the family “sob, and we sob with them, it’s ok, and I think it’s good because we know how sad it is and we have tried as much as we can...” Subject 2 continues that their view changes, “...it’s not about the child, we are caregivers to the family, so it kind of turns around and we take care of them.” This protocol, as well as Subject 1’s specific case, shows that pediatric isn’t viewed as treating the child, but looking at the family system as a whole patient and meeting their needs individually, at whatever stage of life the child is at, from birth, to even after death.

### **Summary**

The aim of the present study was to analyze nurses’ perceptions of parents staying with their chronically ill children during a hospitalization. By using a qualitative research method and interviewing two nurses, one retired from pediatrics in the pediatric intensive care unit, and the other currently still working in pediatrics through the emergency department, this study was able to find data that was well-rounded in the scope of pediatric care. The present literature exposed issues pertaining to parents’ involvement, or lack thereof, as well as how nurses and parents can work together in order to provide the best care possible to the primary patient, the child (Balling & McCubbin, 2001; Berge & Holm, 2007; Lourdes, Nunes, & Noemia, 2012; Power & Franck, 2008; Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009; The Welfare of Children in Hospital, 1959; Vasli & Salsali, 2014; Ygge & Arnetz, 2004).

The current hypothesis stated that nurses emotionally desire parents to participate in the child’s treatment; however, there would be logistical realities that would impede such desires. This was confirmed by the two Subjects interviewed, but in different ways. Both interviewed nurses believed that it was important, if not essential for parents, mostly mothers, to be involved with their child’s healthcare. This is supported by the literature, “[p]arents give the child

emotional support and act as a bridge between the child and hospital staff” (Ygge & Arnetz, 2004, p. 217). Furthermore, the current literature found that parents are able to decrease stress and maintain balance, something that professionals can only do to a certain degree (Sajari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009, p. 121). The only stipulation that the Subjects found occurred when the parent would become a hindrance or obstruction to those providing medical care to their child. While Subject 1 only saw this occur one time in her 13 years in the pediatric intensive care unit, Subject 2 experiences this half the time in the pediatric emergency department.

Working in the pediatric intensive care unit, Subject 1 had extremely difficult and involved cases where children’s lives were actually on the line the entire time. This suggests a need for a more emotional attachment since the nurses and parents have the child’s life in their hands. Subject 2, working in the pediatric emergency department where she had a larger range of medical issues that she encounters. The result of opinions showed that Subject 1 and Subject 2 viewed their jobs differently, and thus described them differently. Subject 1 focused on the emotional needs of the family and child, whereas Subject 2 explained the process from admission to discharge in the pediatric emergency room. The nature and severity of the PICU, compared to the pediatric emergency department exemplifies the discrepancy in the explanation of duties. Furthermore, PICU nurses are very specialized and the job itself requires a great deal of intense commitment. This difference between triage in the pediatric emergency room, and being in the PICU has been shown, through the interviews, to affect how parents and nurses interact and view each other.

Another distinguishing factor includes the caseload for each nurse. While PICU nurse will have, at the most two patients, a pediatric emergency room nurse could have at least four or

five patients at a time. This also changes the dynamic and how different nursing specialties will look at parent interactions.

The current literature available found that parents wanted to be involved as a way to uphold and strengthen the parent-child relationship, even when the child was in the hospital (Power & Frank, 2008; Sajari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi, 2009; Ygge & Arnetz, 2004). This was strongly affirmed by both subjects. However, while the research found that parents wanted to be more involved in the medical aspects of care, but were not sure how to go about being included, neither subject brought this up as a teaching method or something that they even come into contact with in their roles as nurses. This discrepancy should be explored further in future studies.

Education was the one of the most important parts of working with a family with a hospitalized sick child. Subject 1 and 2 explained the need to educate concerning their chronically ill child, as well as explaining the diagnosis and other issues the child might encounter outside of the hospital. The need for not only the time to explain the details of the child's condition, but also the time to answer questions, and repeat any answers is a key point that both Subjects emphasized.

An unexpected topic that both Subjects expressed was end of life and after death care for children. Both subjects were extremely serious and respectful of the process and helping the family in any that they could. This area of pediatric care is often viewed as taboo due to the fact that our society shies away from talking about such topics since it is extremely sad and uncomfortable. Yet, both of the Subjects were more than willing to explain the process and point out that after the child has passed, their jobs are not done. As pediatric nurses their job changes focus from the child to the parents and family.

This view of the family and parents as second patients was a theme established by literature and confirmed by this current study (Callery, 1997). However, whereas the parents viewed being a 'patient' as a negative connotation, nurses viewed the parents of the young patient as 'patients' positively (Callery, 1997, p. 994). Whether it was after the child had passed, or when the child was hospitalized, both subjects focused on not only addressing the child's needs, but also the needs of the parents. This could include making sure they have a chair to sleep in, to talking with the parents and helping them work through the fact that their child is sick,

Both subjects did state that there are physical changes they would want within their work environment. Subject 1 stated that there was an ongoing joke that they made it for children, but also must have thought children would be the nurses. Subject 2 stated that although the improvements are going to help with upholding HIPAA, it does make it difficult for nurses to check on multiple patients at a time. Although Subject 1 did not think any physical change so the PICU would occur, Subject 2 is working in a hospital that is currently renovating and is hopeful that the renovations will help with privacy as well as overall accessibility. Subject 2's view is supported by the fact that head nurses were consulted when the plans were made, whereas no one was consulted with PICU changes when they were implemented.

In order to help keep all patients safe and still protected, pediatric nurses need to be able to work together. Both Subjects stated that the nursing staff in their units felt like a family, and it needed to be like that in order to provide the highest quality of care for their patients. This need for community and a sense of trust among nurses is imperative to providing the best care.

### **Limitations**

This limitations of this study include only have two subjects to interview and then compare. Furthermore, the two subjects are in different places in their lives, Subject 1 no longer working in the PICU, while Subject 2 is currently working in the pediatric emergency room. This discrepancy could skew the findings in that Subject 2 is working with pediatric patients and thus can easily recall incidents, both positive and negative. Subject 1, having worked in the PICU for 13 years and now working in adult medicine, is viewing her experience retrospectively, which could change the way in which she described her experience.

It is practical to consider that Subject 2 could view the interview as a way to express any issues in a safe space where anonymity was stressed throughout the interview. This may have led to more honest answers, or answers that seem honest at the time, but haven't been fully processed by the Subject. From the retrospective view of Subject 1, the comments and statements are being viewed in hindsight, and thus could be focused only on the positive, ignoring or forgetting the negative in order to sustain one's memories and views of the experience of being a PICU nurse. Both Subjects bring potential biases, which are accounted for and balanced by first acknowledging such limitations, and secondly by having one subject answer prospectively and the other retrospectively.

Another limitation to this study is the lack of research and knowledge about PICU nurses in the literature review. Since PICU is such a subspecialty, it could be considered its own pediatric arena, rather than viewing it as another place for pediatric children.

### **Conclusion**

The hypothesis of this study was confirmed in that pediatric nurses want and believe it is necessary or parents to be involved in their chronically ill child's care. Furthermore, it was found that parents are secondary patients. The interviewed subjects expressed that in order to properly

work with children, this study found that nurses need to look at the patient as not only the child, but the family system as a whole. Furthermore, the health and wellbeing of the child is dependent on the parents, and thus viewing them as secondary patients is helping the child patient overall.

### **Practice Implications**

Pediatric nurses need to have patience and understanding in order to help their patients. Being willing to educate parents is imperative to the health of the child. Furthermore, pediatric nurses need to be able to pick up on social cues of parents to provide the care that is in the best interest of the child, whether that is including the parent, or understanding that the parent isn't able to help in the medical situation, but can help after the fact.

### **Research Implications**

Further research should focus on the continued views of pediatric nurses throughout different specialties, if rich research can continue to be found through interviews with nurses, larger changes and views of nurses' perceptions of pediatric pain can be formulated and integrated into the current research.

In addition to understanding how pediatric nurses perceive parental involvement, research should focus on how pediatric nurses emotionally work through their job and avoid negative outcomes, such as burnout or compassion fatigue. By understanding how pediatric nurses' work with children who are living through the negative experience of being in a hospital, research can then be used to help other pediatric nurses and nurses in general to avoid negative outcomes.

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Appendix A



PROVIDENCE  
COLLEGE

INFORMED CONSENT DOCUMENT

Providence College

Nurses' Perception of Patients Staying during Chronically Ill Child' Hospitalization: Learning to  
Speak the Same Language

You are being asked to participate in a research study about your views on parents staying with their chronically ill child during a hospitalization in order help understand possible supports and barriers to a child's care. You were selected as a possible participant because as a pediatric nurse, you are at the forefront of patient care and have the most direct contact with the direct patient and the family. Please read this form and ask any questions that you may have before agreeing to participate in the research.

Researchers from Providence College are conducting this study.

**Background Information**

The purpose of this research is to collect information about what factors contribute to parents' ability to stay in the hospital, how parents staying effect your ability to do your job to the best of your ability, and what would make the experience easier for you as nurses.

**Procedures**

If you agree to be a participant in this research, we would ask you to do the following things: meet with the researcher at your convenience for an interview concerning the research study; discuss your feelings and attitudes openly and honestly to the researcher. Establishing and participating in the interview will be the only participation required. The interview is expected to last at least 10 minutes, but will continue as long as time permits. Due to the fact that you will be expressing feelings concerning patients and their families, as well as how that effects your ability to do your job, there is a chance that you could experience some level of discomfort.

**Risks and Benefits to Being in the Study**

This research has the following risks: First, that there is a small likelihood that you might feel uncomfortable sharing your feelings about your work. Second, you might experience conflicting feelings when asked a question. These are slight, but possible risks that you might encounter.

If, at any point, you feel too uncomfortable to continue the interview, you can terminate your participation in the study and the interview will cease. The resources below are available if you feel that you need emotional or psychological support.

The benefits of participation are knowing that you will be helping to establish the viewpoint of nurses when research concerning parental involvement often focuses on the parents. By providing honest information, you will be adding to research that aims to improve the quality of hospital stays for chronically ill children and their family. Additionally, you could benefit by

understanding your own personal feeling about parents staying with their children, allowing for the potential of personal growth.

### **Confidentiality**

The records of this research will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a participant. Research records, including the recordings and transcriptions, will be kept in a locked file, and access will be limited to the researchers, the college review board responsible for protecting human participants, and regulatory agencies. The original data will be destroyed within seven years after the study is finished, including recordings and transcriptions.

### **Voluntary Nature of the Study**

Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the College or with the researcher. There is no penalty or loss of benefits for not participating or for discontinuing your participation.

### **Contacts and Questions**

The researchers conducting this study are Nicole Toscano, senior undergraduate Social Work and Health Policy and Management major, and Dr. Kranz, the overseeing Social Work professor at Providence College. You may ask any questions you have now. If you have any questions later, you may contact Nicole Toscano at [ntoscano@friars.providence.edu](mailto:ntoscano@friars.providence.edu) or (978)-399-8248, or Dr. Kranz, at [kkranz@providence.edu](mailto:kkranz@providence.edu), or 401-865-1581.

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about (1) concerns regarding this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact the Chair of the Providence College Institutional Review Board (IRB). Contact information for the IRB Chair can be obtained from the Office of Academic Affairs (Provost), Harkins 208, (401) 865-2195 or [irb@providence.edu](mailto:irb@providence.edu).

You will be given a copy of this form for your records.

### **Statement of Consent**

I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research. I am at least 18 years of age.

Print Name of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Person Obtaining Consent: \_\_\_\_\_ Date: \_\_\_\_\_

Appendix A.1

Addendum to the Informed Consent Form

Audio/Videotape Agreement

We are planning to audiotape you during this study. You have the right to refuse to be recorded. If you do so, there is no penalty and you will still be able to participate.

\_\_\_\_\_ I give permission to be audio/videotaped (please answer next question).

\_\_\_\_\_ I do NOT give permission to be videotaped (skip to signature line).

If you gave permission to be audiotaped: Your audiotape and transcription will be erased at the completion of this study unless you give permission below for it to be kept. If you give permission for your audiotape to be kept, it may be played at professional meetings or for educational purposes. Your name will never be used, and the audio/videotape will never be used in any other context.

\_\_\_\_\_ I give permission for my audio/videotape to be kept.

\_\_\_\_\_ I do NOT give permission for my audio/videotape to be kept.

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Appendix B

## Guided Interview Data

This appendix presents the semi-structured interview method used by the researcher for the participants. Any additional follow-up questions or questions added to find additional information based on a participants response can be found in the transcription of the interviews, which can be found if requested from the researcher. These interview questions begin after the consent form is discussed and signed. Some of these questions are put together in order to prevent the researcher from asking the same question multiple times.

Demographics

I am going to start by asking some simple questions to have the most accurate data.

1. How would you identify your gender? \_\_\_\_\_
2. How old are you? \_\_\_\_\_
3. How do you identify your Ethnicity/Race (African American, Asian, Pacific Islander/Hawaiian, American Indian/Alaska Native, Caucasian)? \_\_\_\_\_
4. Do you identify as Latino(a) or Hispanic? \_\_\_\_\_
5. How long have you been a pediatric nurse? \_\_\_\_\_
- 5a. Have you been a nurse in specialties other than pediatrics? \_\_\_\_\_

Guided Interview Questionnaire

1. What are your normal duties as a pediatric nurse?
2. Is there a hospital protocol that you follow when parents stay with their chronically ill children?
  - 2a. Are parents allowed to stay in the hospital overnight with their chronically ill child?
3. Do you work with parents of chronically ill children?
  - 3a. If yes, what does that entail?
4. Do you find that chronically ill children are influenced, and or impacted, if their parents stay with them?
  - 4b. If yes, how so?
5. Do you find that parents are influence, and or impacted, from staying in the hospital with their chronically ill child?
  - 5b. If yes, how so?
6. If parents stay with their chronically ill child, does impact your daily routine and responsibilities? If so, how?
7. If parents do stay overnight, does this impact your routine as a nurse?

8. Are there any challenges that you face when a parent is present during a patient's stay?

If difficulties are discussed:

9. What would you change to make your job easier when parents stay with their children?

10. Do you think these changes are likely? Why or why not?

11. Do you have any other comments?

Thank you so much for your time. I really appreciate your open and honest opinion! If you have any questions, please don't hesitate to contact me through the information on the consent form. Please remember that there are resources that you can reach out to after this interview, which can also be found on the consent form. Your interview will remain confidential and any information that you provided will be de-identified in the research study. Do you know of any other pediatric nurses who would be willing and able to participate in this research study? If so, can you provide a way for me to contact them? I can withhold your name or give it as a reference; whatever makes you most comfortable. Thank you again, have a great day!

## Appendix C

### Debriefing Statement

#### Nurses' Perceptions of Parents Staying during Chronically Ill Child's Hospitalization: Learning to Speak the Same Language

Thank you again for agree to participate in this study. If after completion of this interview you experience any triggers or uncomfortable issues related to the study, I have provided a list of resources that can assist you below:

Delta Consultants  
2 Regency Plaza  
Providence, RI  
401-421-1405

Delta Consultants of South County  
24 Salt Pond Road  
Wakefield, RI 02879  
401-789-3694

East Bay Mental Health Center  
2 Old County Road  
Barrington, RI 02806  
401-246-1195

The hypothesis made going into the semi-structured interviews stated that nurses would emotionally like to have parents involved and a part of their child's treatment process, however these emotional desires would be outweighed by logistical realities including having multiple cases at one time, not having the ability to spend the time with parents, and parents becoming patients themselves, which would be time consuming and prohibitive to the nurse's ability to perform his or her job. The two interviews conducted supported the stated hypothesis, but in different ways.