Culturally-Informed Family Education in the Infant Population

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Author Note

I have no conflicts of interest to disclose.

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Abstract

Working with infants and families can be as challenging as it can be rewarding for healthcare professionals, particularly when working with families of diverse cultures. Many cultures perform various parenting practices which are viewed in the western world as odd or even dangerous. Addressing these practices is difficult and creates a barrier to providing equitable, family-centered care. The purpose of this capstone project was to provide education to healthcare practitioners working with high-risk infants in the NICU and outpatient settings. Interviews were administered with NICU and outpatient staff to gain understanding of staff perceptions of family-centered care. A pre-survey was distributed to NICU nursing and therapy staff, outpatient pediatricians, and outpatient therapists to gain baseline knowledge of staff awareness and understanding of cultural parenting practices. An educational PowerPoint was provided to staff along with a post-survey and quiz to measure success of the education. Staff demonstrated increased knowledge and confidence in providing culturally-informed education to families regarding these practices. This project emphasized the importance of ongoing cultural education for healthcare providers working with the infant population.

Keywords: Family education, infants, cultural humility, NICU, family-centered care

Culturally-Informed Family Education in the Infant Population

Infants in the Neonatal Intensive Care Unit (NICU) require more specialized care than those in regular nurseries. They have been born too early or too small and require twenty-four hour care from many different disciplines of healthcare, including medicine, nursing, and various therapies. The role of occupational therapy (OT) practitioners in the NICU is to assess and provide interventions for development, positioning, and regulation as well as providing education and support to the family as they transition from the NICU setting to home (Craig et al., 2018). Occupational therapists must take into account the person as a whole and consider all client factors of the families when providing education, including cognition and culture. In order to optimize parents' adherence to specific precautions and home exercise programs, therapists need to ensure that parents have a good understanding of the materials provided prior to discharge and provide quality outpatient follow-up services.

The capstone site was a Federally Qualified Health Center in downtown Indianapolis that serves the Indianapolis area, particularly the vulnerable populations that reside in Marion County. Many of these populations include those of low socioeconomic status, minorities, and those who do not speak English as a first language (Site stakeholder, personal communication, March 19, 2021). Because of this cultural divide, it is difficult for practitioners to educate families on safe parenting practices if it does not align with their culture (Site mentor, personal communication, March 19, 2021). If parents do not completely understand what they are being taught and adhere to it, the safety of these vulnerable infants could be at risk (Site mentor, personal communication, March 19, 2021). Additional research and education is needed for the therapists and staff who work in the site NICU and Infant Clinic to gain better understanding

across the multitude of cultures served in this patient population. The focus of this research will be geared toward increasing equity and justice in parent education.

Needs Assessment

As stated above, the primary problem in the site NICU and Infant Clinic is a cultural divide between practitioners and families which results in decreased adherence to family education. Families served in these settings include a large number of Spanish-speaking families, African refugees from the Congo and Somalia, families of low socioeconomic status who may be under- or uninsured, and those with little to no formal education (Site stakeholder, personal communication, March 19, 2021). Topics of education include safe sleep, specific conditions that can occur in preterm infants such as brachial plexus injury and torticollis, recommendations for general development such as tummy time, and environmental considerations to prevent intraventricular hemorrhage. If families do not adhere to these recommendations, infants may have difficulty with regulation or issues with behavior and motor planning down the road. In the worst cases when safe sleep guidelines are not followed, Sudden Infant Death Syndrome may occur (Site mentor, personal communication, March 19, 2021). When asked to identify barriers to education, the common consensus is that staff lack knowledge of other cultures in order to provide culturally-informed education to the diverse families they serve. The therapy staff believe that with more education on parenting practices of different cultures, practitioners will be able to integrate those habits into education that the families will be able to comprehend and adhere to.

Purpose Statement

The purpose of this project was to provide education to the staff of the NICU and Infant Clinic of the site and empower them to provide more equitable care for the diverse families served in these settings.

Literature Review and Gap Analysis Statement

Family-centered care was the primary guiding concept of this project's execution. Family-centered care focuses on collaboration with families and consulting with families as experts on their children. The key principles of family-centered care include: information sharing, respecting and honoring differences, partnership and collaboration, negotiation, and care in the context of family and community (Kuo et al., 2012). These principles are crucial when it comes to family education in the infant population.

Family-Centered Care and Occupational Therapy

One recommendation for supporting family involvement in the NICU includes incorporating family members as members of the healthcare team. This would involve encouraging families to participate in as much "hands-on" care as possible with their child, including skin-on-skin contact and coaching families in how to comfort their child and minimize stress (Craig et al., 2015). Gooding et al. (2011) report that NICU programs that implement family-centered care principles demonstrate lower NICU stays, increased parent confidence in caregiving, and even increased satisfaction in NICU staff members. OT's role in providing culturally-informed education is to empower families so that they may fulfill their role as a parent while their child is in the NICU and following discharge.

Occupational therapy prides itself on being a profession that is client-centered. However, in a pediatric setting where parents and family are the foundation of a child's life, "client-centered" is often replaced with "family-centered" (Fingerhut et al., 2013). Practicing

OTs have identified many ways in which they incorporate family-centered care into their everyday practice, including working collaboratively in a team-based manner with families (Humbert et al., 2020). However, Pereira and Seruya (2020) state that inconsistencies in the definitions of family-centered practices as well as a lack of education on how to implement these practices serve as barriers to incorporating them into their own practice. Thom (2018) found that language differences and time were the greatest barriers for OTs working with Hispanic/Latino families. These barriers are common for OTs working with diverse populations in a variety of settings, and it is these barriers that cause gaps in providing family-centered care in OT practice.

Identified Gaps in Family-Centered Care

When it comes to identifying gaps in family-centered care, there is no better source than the families themselves. In a study by Sigurdson et al. (2020), former NICU families identified one major gap in family-centered care to be power dynamics and judgment from the nursing staff and other providers, many of which were perceived to be racially or socioeconomically driven. Gafni Lachter and colleagues (2020) questioned both practitioners and families on their perspectives on family-centeredness of services being provided and the families' ratings were significantly higher than those of the therapists except in the domain of providing specific information, which demonstrates a need for greater family-centered education in this setting. In order to create more equitable care in the NICU and Infant Clinic, staff must have an understanding of power dynamics in healthcare as well as parenting practices across cultures in order to provide greater family-centered care.

Guiding Models

While there is little evidence to support integration of culture into occupational therapy education, there is evidence to support cultural humility and occupational justice. Cultural

humility is defined as a "lifelong, learning-oriented approach to working with people with diverse cultural backgrounds and a recognition of power dynamics in healthcare" (Agner, 2020). This supersedes the dated term of cultural competence as cultural humility focuses on constantly learning about different cultures, recognizing our own implicit biases, and encourages acknowledgement of the power dynamics that exist between healthcare practitioners and those whom they serve. Occupational therapists in particular have an opportunity to learn more about these power dynamics and use them to create a more client-centered, collaborative approach to treatment (Agner, 2020). Evidence supports the practice of cultural humility in healthcare; in a concept analysis by Foronda et al. (2016), attributes linked to cultural humility included openness, supportive interaction, and self-awareness. Cultural humility is not only applicable to different racial and ethnic groups, it is also related to socioeconomic status. Arpey et al. (2017) state that those of lower socioeconomic status perceive that practitioner bias impacts their care and their interactions with practitioners. By engaging in critical self-reflection, we can recognize our own biases not only towards those of different racial backgrounds, but those of different socioeconomic backgrounds in order to provide the most equitable care.

Occupational justice is the idea that every individual has the right to engage in preferred occupations equally (Boyt Schell & Gillen, 2019). Unfortunately, many forms of occupational injustices exist, and healthcare practitioners may be contributing to these injustices. For example, if a mother wants to hold her child a certain way and a practitioner tells her that it is "wrong" and dismisses the mother's way outright, that practitioner is engaging in occupational marginalization by setting an expectation of how that mother "should" engage in her role as a mother without regard to her culture or values. Occupational justice emphasizes the "enablement of differences in occupational participation" (Townsend & Willcock, 2004), meaning that the

practitioner should acknowledge and incorporate the mother's different perspective into family-centered education. By employing cultural humility and occupational justice practices into the site NICU and infant clinic, therapists and practitioners will be able to give more equitable treatment and education to the families that they serve.

Capstone Plan

As previously stated, the goal of this project was to improve equity and family-centered care in the site NICU and infant clinic by increasing cultural humility among the staff. It was determined between the capstone student and site mentors that the greatest way to achieve this was through staff education on various parenting practices across diverse cultures. Goals and objectives for the project were approved by the site mentors and faculty mentor are as stated below:

Project Goal 1: The student will collaborate with the occupational therapists working in the site NICU and infant clinic to identify a collaborative purpose for the capstone project, use evidence to identify "gaps" between best practice and current practice, and develop a project to benefit the organization and families served.

Objective 1: The student will gather information from site stakeholders and searching literature for best practice to identify "gaps" as well as determine needs of the site, current resources, and resources they are lacking in order to conduct a gap analysis and needs assessment.

Objective 2: The student will review and examine literature relevant to family- and culturally- centered care in order to have an evidence-based foundation for the proposed project.

Objective 3: The student will utilize knowledge compiled from the gap analysis,

needs assessment, and literature review in order to develop a plan for the proposed doctoral capstone project.

Project Goal 2: The capstone student will create an e-learning module focusing on implicit bias and power dynamics in healthcare as well as parenting practices across cultures to empower staff working with the infant population to provide culturally-informed family education.

Objective 1: The student will search the literature for research related to parenting practices across diverse cultures.

Objective 2: The student will collaborate with mentors to create modified family education based on the cultural needs of the families served.

Objective 3: The student will compile research and modified education to create an e-learning module and distribute it among the multidisciplinary staff.

Project Goal 3: The NICU and outpatient pediatric staff will demonstrate improved self-reported confidence and competence in providing education to culturally diverse families as evidenced by a majority of participants reporting increase in knowledge and confidence by one point or higher on post-survey.

Objective 1: Within 1 week of release of the pre-survey, 70% of recruited staff will have completed the pre-survey.

Objective 2: Within 2 weeks of release of the e-learning module, 65% of recruited staff members will have completed the module and post-survey.

Objective: 90% of participants will receive 80% or higher on quiz taken following the e-learning module.

Capstone Process

Orientation to the sites took approximately two weeks as the student was working in both the NICU and outpatient clinic. Separate meetings were held with the inpatient and outpatient site mentors during orientation to discuss the needs of each site and specifics regarding the project. A meeting was held on March 3, 2022 between the capstone student, site mentor, and the inpatient therapy manager to discuss logistics of the project. A second meeting was held on the same day between the capstone student and NICU nursing manager and educator regarding the inclusion of nursing staff in the project. The project pre-survey was sent to participants via email on March 9, 2022 and the presentation and post-survey were sent via email on March 30, 2022. Regular informal meetings were held with the site mentors weekly to touch base on the project timeline and discuss any questions or concerns.

Methods

Project Design

Initially, this project was going to be an in-service provided to the multidisciplinary NICU and infant population staff regarding cultural humility and parenting practices across cultures. However, to comply with COVID-19 precautions, it was decided between the site mentors and the capstone student that an e-learning module would allow staff to be provided education in a way that allowed for social distancing. In turn, this change improved accessibility and sustainability for the project by allowing staff to view it in their own time and managers to include it in new hire education. This e-learning module included education on cultural humility and power dynamics in healthcare, various parenting practices in different cultures, and how to approach family education in a culturally-informed manner. This education was provided through a PowerPoint presentation and sent to staff as a PDF file via email. Approval for this

project was obtained by the Indiana University Internal Review Board as "Not Human Subjects Research."

Recruitment

Staff included in this project were those who provide family education in the NICU and outpatient setting. This consisted of inpatient therapists and nursing staff in the NICU as well as OTs, speech therapists, and pediatricians in the outpatient setting who work with infants. Recruitment was completed through meeting with nursing leadership to promote the project and through word of mouth from the site mentors to their colleagues. An email was sent to all potential participants containing a letter discussing the aim of the project (Appendix A) and a link to the project pre-survey. Contact was made with participants via email.

Data Collection

A pre-survey was sent to all potential participants. Changes were made to the pre-survey from the initial survey plan in order to gain better understanding of the staff's baseline perceptions of diverse parenting practices. Pictures and video clips of various parenting practices were included in this survey with follow up questions about the participants' perceptions of these practices. For example, an image of parents co-sleeping with an infant was used (Appendix B). Follow-up questions such as "Do you find co-sleeping problematic? Why or why not?" were included after the clip. Other practices included in this survey were: babywearing, force feeding, bottle propping, and holding an infant by the arm. General questions regarding participants' perceptions of their own knowledge and confidence in providing culturally-informed education were also posed.

Qualitative data was collected via interviews with OTs in the inpatient and outpatient setting, as well as a speech therapist in the outpatient setting and the Family Support Coordinator

in the NICU. Each interview was approximately thirty to sixty minutes. For the sake of convenience and time, the outpatient OT and speech therapist were interviewed together. Questions focused on staff perceptions of family-centered care in the infant population as well as staff supports and barriers to family-centered care (Appendix C). Interviews were transcribed in real-time.

Supports and Barriers

Support for this project included the interest of the site mentors and management who helped promote and advocate for the project. The site mentors have a combined sixteen years of experience in this setting and were able to provide insight into different parenting practices they have seen from various cultures. The largest barrier was scheduling conflicts making it difficult to arrange meetings with staff. Increased caseloads in their respective settings made it difficult for the site mentors to schedule times to meet with the capstone student. An unexpected barrier was the pushback received regarding the content of the e-learning module. Initially, it was agreed upon between the capstone student and site mentors that the goal of this education was to help staff meet families where they are and address education in a culturally-informed manner. However, one topic addressed in the e-learning module was parents co-sleeping with infants. Co-sleeping is done for a variety of reasons, cultural or otherwise, and the literature states that regardless of traditional "safe sleep" education, families will continue to co-sleep (Gaydos et al., 2014). In order to address this, a link to safe co-sleep modifications was included in the module. While some viewed it as a way to work with parents to make unsafe practices as safe as possible, others saw it as a liability and did not want it included in the presentation. After much discussion over the course of a week (delaying the release of the presentation), it was decided that the co-sleeping modifications would not be included, however, a handout providing safe sleep

alternatives to traditional cribs was included to address one common barrier to safe sleep in this population. While safe co-sleeping was not addressed in this particular project, it is important to note that this started a dialogue within the NICU setting of how to work with families when they endorse co-sleeping despite being provided safe sleep education.

Capstone Project Evaluation and Results

Data for evaluation of the project was collected via an online quiz to assess effectiveness of the education as well as self-report questions to assess perceptions of the participants after completing the e-learning module. Pekrun (2020) states that self-report is important to gain understanding into a learner's emotions and metacognition as it relates to education. Salas-Morera et al. (2012) state that online quizzes have a positive impact on a learner's academic performance. The site mentor assisted in creating the quiz in order to make it more applicable to clinical practice by using the quiz questions to create clinical scenarios in which the staff would have to provide culturally-informed education.

Interviews

Interviews were held with four different staff members including two outpatient therapists, one NICU therapist, and the NICU Family Support Coordinator regarding their perceptions of family-centered care in their respective settings. Three themes were recognized from these interviews: Meeting Families Where They Are; Education, Curiosity, and Asking Questions; and Communication and Engagement. Meeting families where they are includes practices that adapt to a family's culture and context. The outpatient therapists mentioned asking about how parents do things at home and work from there rather than assuming families do what is considered "normal." The inpatient therapist included the importance of understanding the trauma that comes with having a child in the NICU and being empathetic to that situation.

Importance of education, curiosity, and asking questions includes not assuming how a family functions and always asking questions in order to gain further insight into their lives. It is also important to be curious about other cultures and ask questions to gain understanding. The Family Support Coordinator mentioned that this is a lifelong process and there is always room for improvement when it comes to understanding other cultures. Finally, communication and engagement, not just between staff and families, but within the staff. The inpatient practitioners mentioned the importance of communication between staff as many people come from different hospitals and have their own set of expectations when it comes to family-centered care; it is important to have department-wide communication and standards on what it means to be family-centered. Communication with families can be as simple as being sure to use a translator when necessary. However, the Family Support Coordinator also mentioned the importance of "unstructured communication" that is not related directly to information regarding the infant, but rather allows parents time to process what they are going through. All of these themes are what staff members stated are important when it comes to family-centered care. All of the staff interviewed believed this project would provide education necessary to improve family-centered care in these settings. As one outpatient therapist stated, "It would be nice to not have to have twelve years of experience to know how to [work with] these families."

Pre-Survey Results

In the pre-survey, participants showed the greatest amount of discomfort with practices with which they also showed the highest rates of unawareness; these practices were force feeding and handling an infant by the arm. In the free text responses, participants claimed that for some practices, such as babywearing, they felt that they did not have enough knowledge to make an informed decision on whether they viewed the practice as problematic or not. However, many

acknowledged that in other cultures these practices have likely been performed for generations and are not seen as problematic or dangerous. Some empathized with families and stated they could understand why these practices would be performed regularly due to a lack of time or resources.

Quiz and Post-Survey Results

The total number of staff who participated in the education and post-survey was 22. Two of these participants did not complete the pre-survey and were therefore excluded when comparing data between pre- and post-survey. A 5-question quiz was included in the post-survey to evaluate the effectiveness of the e-learning module. This quiz was similar to one that would have been included had the module been distributed via HealthStream. The mean score of the quiz was 4.59. Distribution of scores are demonstrated in Figure 1. 90.91% of participants reported feeling moderately, very, or extremely knowledgeable after completing the educational module. On the post-survey, 87.28% of participants reported feeling moderately, very, or extremely confident, compared to 40.47% on the pre-survey (Figure 2).

Figure 1

Distribution of Quiz Scores Amongst Participants

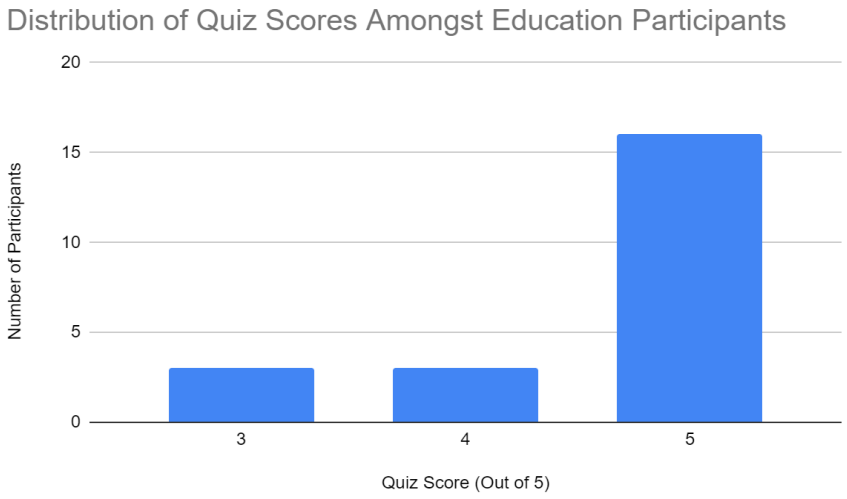
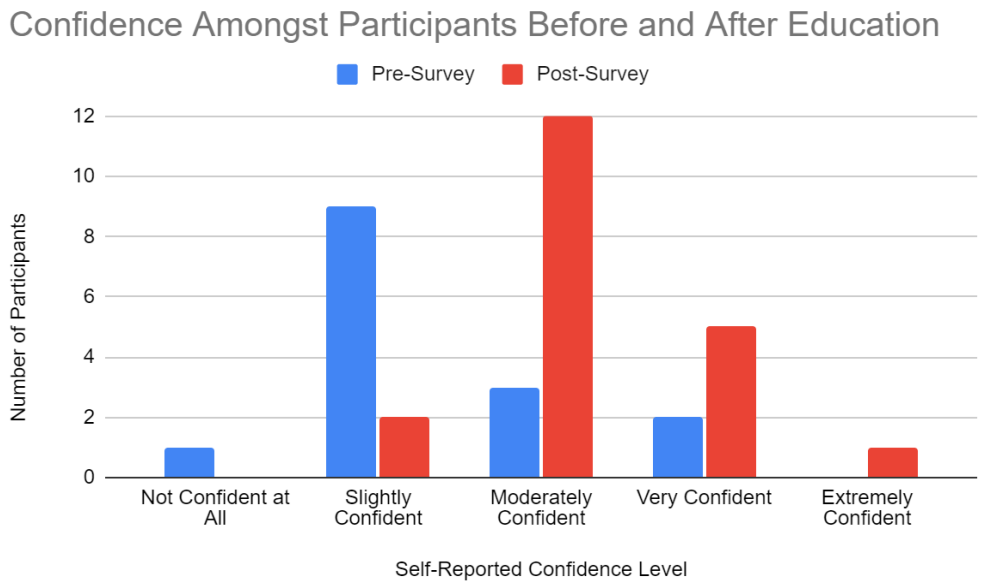


Figure 2

Confidence Amongst Participants Before and After Education



Discussion

The overall goals of this project were to gain understanding of current staff perceptions of cultural parenting practices in the context of family education and family-centered care in the infant care setting and increase staff knowledge and confidence of addressing cultural parenting practices through an e-learning module. One gap identified prior to the start of this project was lack of staff knowledge on parenting practices across cultures. The objective was to have 90% of participants score 4/5 or higher on the quiz and 86.4% of participants achieved this. This demonstrates the need for continued education for staff in these settings. Through the education provided in this project, staff have increased their knowledge and confidence in providing culturally-informed education to families.

Limitations

Limitations to this project include self-report bias and that even though staff report that they feel knowledgeable and more confident in providing culturally-informed education, this

does not mean that they will change the way they provide education in everyday practice. Unfortunately, due to time constraints, important data regarding families' perceptions of the education they receive and how it relates to their own cultural practices was not able to be collected.

Impact and Sustainability

This project made people uncomfortable and forced them to consider their own biases towards the families they serve. It provided a perspective that many clinicians had not previously considered and gave them an opportunity to look at the things from the point of view of underserved families. This project not only shone a light on an aspect of clinical practice that is often overlooked, it started a conversation that could result in a cultural shift in the NICU and outpatient setting over the next several years. Many practitioners in this setting are now aware of several cultural parenting practices and are equipped with the tools they need to address these practices in a culturally-informed manner. The education was well received. Participants commented in the post-survey that this project was eye-opening and exposed them to many practices of which they were not aware. One commented that they appreciated that the practices discussed were of cultures that are most frequently seen at the site.

The e-learning module created for the project will be added to new hire education for therapy and nursing staff in the NICU to continue to educate incoming staff on the importance of culturally-informed education. This project also started many conversations in the NICU and outpatient settings regarding approaches to family education and raised questions that will keep staff curious and continuously trying to learn more.

Conclusion

The purpose of this project was to provide education to the staff of the NICU and infant clinic of the site and empower them to provide more equitable care for the diverse families served in these settings. This project made staff uncomfortable and forced them to consider their own biases when it comes to parenting practices outside of the "norms." This project fulfilled its purpose by increasing staff knowledge and confidence when it comes to providing equitable family education, and will hopefully continue to do so for years to come.

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Appendix A

Recruitment Letter

To Whom It May Concern,

My name is Claire Lindenmayer. I am an Occupational Therapy student from IUPUI completing my doctoral capstone experience in the NICU and outpatient Infant Clinic. In collaboration with my mentors, I am completing a project to increase cultural humility and family-centered care in these settings. My aim through my project this semester is, through an e-learning module, to educate employees on various parenting practices across cultures that may differ from typical American recommendations and practices. My hope is that this will empower employees to educate the diverse families served in a way that is culturally-informed.

I am sending out this survey asking for perceptions of parenting styles across cultures. This survey will contain pictures and video clips of how parents of diverse cultures feed their children, handle and/or carry their children, and put their children to sleep. I ask that you please participate in this survey and answer honestly, as it is crucial to understanding your perceptions of these practices before participating in the e-learning. The survey will take 20-30 minutes to complete. Responses will be completely anonymous and for the purposes of my capstone project only. I invite you to keep an open mind while participating in this survey and e-learning and remember that cultural humility is a process of lifelong learning and growth. Please do not hesitate to reach out to me at the below email address with any questions or concerns.

Thank you in advance for your participation,

Claire Lindenmayer, OTS

celinden@iu.edu

Appendix B

Pre-Survey Image

(Fortunata, 2020)

Appendix C

Staff Interview Questions

1. How long have you worked in the NICU/Infant Clinic?
2. What does ‘family-centered care’ mean to you?
3. Do you believe you incorporate family-centered care in your practice? Why or why not?
4. What are your strengths that can help you provide family-centered care?
5. What barriers are keeping you from providing family-centered care?
6. What is most important to you in regards to improving your family-centered care?
7. Does working with diverse populations make you better at your job? Why or why not?
8. What benefit will this capstone project have on family-centered care?