Published in final edited form as:
J Perinat Neonatal Nurs. 2009 ; 23(2): 159–170. doi:10.1097/JPN.0b013e3181a2cacc.

Supporting Parents' Decision Making Surrounding the Anticipated Birth of Extremely Premature Infant

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Introduction

Parents who are at risk of giving birth to an extremely premature infant, 22 to 25 weeks gestation can find themselves faced with urgent treatment decisions for their unborn infant that have life-altering consequences.[1] While the individual medical management options may differ based on the individual case factors, decisions can include elective termination of the pregnancy, medical transfer to a specialized medical center, decisions about the mode of delivery (Cesarean or vaginal), the degree of resuscitative effort at birth, and comfort care. [2] Many experts advocate for involving parents in these decisions prenatally because of the high mortality and morbidity for extremely premature infants, which includes necrotizing enterocolitis, retinopathy of prematurity, intraventricular hemorrhage, and cognitive and physical disabilities 1, 3–8, and increased risk for mortality through childhood.[8] Despite the recommendation for involving parents in decision making, there is limited evidence to base guidelines for involving parents. In this article, we describe a case from a larger collective case study (subsequently referred to as the LiSD study) which is examining the decision making and the decision support needs of parents regarding life support decisions made over time prenatally and postnatally for extremely premature infants from the perceptions of parents, physicians, and nurses. For this case study, because the infant was stillborn, we focus on the decisions that were made during

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the antenatal hospitalization of the mother, the support the parents received, and advice for health care professionals to improve care to families faced with these decisions.

Background Information

A number of authors have addressed the legal and ethical implications of care for the infant born at the threshold of viability.[9–13] There are no state or federal mandates regarding treatment for extremely premature infants in the U.S. However, in last decade there has been an increase in aggressive obstetric management and neonatal resuscitation for threatened preterm births.[4] According to the American Academy of Pediatrics (AAP), all management decisions regarding the birth and subsequent care of the baby should be made jointly by parents and physicians.[2] The American College of Obstetricians and Gynecologists offer similar guidelines stating that the, "decision to withhold or withdraw support should not be made entirely on the basis of gestational age or birth weight, but should be individualized based on the newborn's condition at birth, survival and morbidity data, and the parents' preferences." [14](p. 621) Both the AAP the survival and morbidity rates.[2, 14] According to ACOG, there is sufficient evidence to inform parents that the survival rate for newborns increases from 0% at 21 weeks to 75% at 25 weeks and that babies born before 24 weeks are less likely to survive and are at an increased risk of disability. [14] The AAP additionally notes that for babies who are ≤23 weeks, it may be appropriate not to initiate resuscitative efforts and that parents should be informed that resuscitation decisions made prenatally may be re-evaluated in the delivery room. [2]

Nursing organizations, such as the American Nurses Association (ANA), Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), and National Association of Neonatal Nurses (NANN), encourage nurses to advocate for their patients' rights.[15–17] Provisions 2 and 3 of the ANA Code of Ethics for Nurses focuses the nurse's commitment to the individual, be it mother or child, and the family.[15] The nurse also "promotes, advocates for and strives to protect the health, safety and rights of the patient" (p. 143). The NANN position statement on NICU nurse involvement in ethical decisions supports a team approach to decision-making and views the nurse as integral to the process.[17] Parents often depend on nurses to understand and make meaning of the information they are getting.

Controversy revolves primarily around who is making the decisions for babies born at 23 to 24 weeks. [18] This area is considered to be a "grey zone" where professional recommendations often favor examining each case individually and eliciting parents' wishes regarding treatment. [19] This is commensurate with the bioethics literature in which there is a general consensus that when treatments are experimental and outcomes uncertain, parents should have the right to make informed decisions. [10, 12, 18, 20]

Despite this apparent agreement, a recent study of neonatologists found that for infants between 23 and 24 weeks with birth weights of 500 to 600 grams, only a third of the participating physicians felt that parental preference should decide whether or not the baby should be resuscitated in the delivery room. [21] Thus, while shared decision-making between physicians and parents is often advocated as the ideal way to make decisions for extremely premature babies, it does not necessarily reflect clinical reality. [22–25] Physicians' perceptions of the extent to which parents want to be involved in decision-making often differ from parents' self-reports of their level of involvement. A study by Zupancic et al., found that while most of the physicians interviewed believed that parents preferred to be advised rather that make their own decisions about pregnancy, only 27% of the parents agreed with this perspective.[26]

The limited research in the area of parent involvement in perinatal decision making suggests that parents need information, advice, and recommendations from physicians to be involved in decision making. [27, 28] Traditionally nurses have played a key role in helping parents to understand information and provide encouragement, support and hope.[29, 30] In many cases, the presentation of information is as important as the information itself. When parents are asked to discuss conversations with providers, many focus on aspects of the conversations, such as the support they received from physicians, their stress level, or their own values or beliefs.[28, 29, 31] Several investigators have found that while some parents prefer to be passive in decision-making, a majority of parents want to participate actively in decision-making about their babies.[26, 27, 32–35] Even when parents prefer not to make decisions, they generally want to be included in discussions, receive information, and have their concerns understood by providers.[27, 36]

The consultation between women at risk of a preterm delivery and their physicians generally focuses on short- and long-term possible outcomes. [22, 26, 28, 37, 38] The degree to which subjects such as, desired parental role, quality of life, or experience with special needs children, are discussed in the prenatal consultation varies. [22, 28] Furthermore, when parents and providers are interviewed about the content of the prenatal encounter, there is often discontinuity between their respective accounts regarding what treatment options were discussed and decided upon.[27, 28] Thus, because of the limited and discrepant findings in the research, further investigation into the needs of parents regarding their involvement in decision making is needed.

Conceptual Framework

The Ottawa Decision Support Framework was used as the conceptual framework for the LiSD study. This framework can be used to help clients and providers make decisions about treatment for medical conditions. 39 This framework has three elements: (1) assessing client and practitioner determinants of decisions, (2) providing decision support, and (3) evaluating quality and outcomes of decision. [40] The LiSD study focused on the first element of the framework, assessing determinants of decisions. This element includes: client and provider sociodemographic and clinical characteristics and perceptions of the decisions (e.g. knowledge and expectations); perceptions of important others about the decisions (e.g. support and roles); and personal (e.g. experience and skills) and external resources (e.g. support) used to make the decisions. 39, 40

Methods

Sample

The case study presented here is one case from the LiSD study and it focuses on data collected from a husband and wife and their health care providers (one physician and two nurses). Inclusion criteria for the larger study included parents at least 18 years of age who were English speaking and had participated in a prenatal discussion with a physician regarding treatment decisions for their infant due to threatened preterm delivery (between 22 0/7 and 25 6/7 weeks gestation). In the LiSD study, health-care providers included physician(s) who had talked to parents about life support treatment decisions and nurse(s) who were identified by parents as being supportive and helping explain information.

Measures

Three types of measures were used: interview guides, a demographic data collection form and a medical chart form (for maternal and infant medical history and documentation of discussion about life support decisions). For the LiSD study, there were a total of four types of semi-structured interview guides (prenatal, postnatal, stillbirth, end-of-life) with different wording for the parents and health care professionals (physicians and nurses). Interview guides were based on the Ottawa Decision Support Framework. For this case only the prenatal interview guides were used.

Data Collection

Data collection for this case, as well as the LiSD study, was implemented using strategies for sensitive research. [41], [42] The names of the individuals in this case have been changed. Recruitment occurred after a professional staff member at the hospital obtained the mother's (Susan's) permission for the principal investigator (PI) to contact her. The PI (KK) then contacted Susan, and arranged for an interview, which was conducted on the same day. The interview was done during Susan's antenatal hospitalization after she had spoken to a physician about treatment decisions and before she gave birth. Per IRB protocol, written, informed consent was obtained from both Susan and her husband, John, before the PI (KK) conducted the interviews. The parents gave permission for the nurse co-investigator (TS) to conduct interviews with the physicians and nurses. All interviews were digitally recorded and held in private in a hospital room with separate interviews for Susan and John. At the end of the first interview, demographic and medical chart data were collected and specific information to identify the physician and nurses was obtained.

After the parents were interviewed, the nurse co-investigator called the physician and nurses to discuss the study and determine their willingness to participate. There was one maternal-fetal medicine physician (MFM), one obstetrical nurse (RN) and one neonatal nurse practitioner (NNP) identified prenatally. After giving consent, the physician and nurses were interviewed individually over the telephone per their request. The physician interview was conducted 14 days after the parents' interviews, and the nurse interviews were done 8 days after the parents' interviews. Demographic data were obtained for each health care provider at the end of the interview.

For the LiSD study, parents were contacted every week until 25 weeks gestation or delivery of the infant to ask about changes in life support decisions. For each case, postnatal interviews were conducted regardless of infant outcome. If the infant was born between 22 and 25 weeks gestation, parents and infants were also followed for the first 28 days of the infant's life or until two months of age if the infant was determined to be clinically unstable using predetermined criteria. Per study protocol, parents whose infants were stillborn were given an option to participate in a post-birth interview to continue to tell their story, offer any additional advice, and receive a book or other gift. Susan and John declined the interview but accepted a sympathy card and a book for bereaved parents.

Data Management and Analysis

The procedures in place for data management and analysis for the LiSD were followed for this case. The audio data were sent to a transcription agency via a secure FTP server. Once the transcripts were returned, they were verified for transcription accuracy by a research assistant on the research team. For this case study, The Ottawa Decision Support Framework served as the framework for data management, analysis and the following presentation of findings. Data were coded and entered into Atlas-ti software. Data for one-third of all of the cases (including this one) were double coded, meaning two members of the research team coded the interview transcripts independently and then met to compare coding and recode until agreement was reached. The other data (medical and demographic information) were entered into Excel. Case summaries were created for each interview transcript. Data analysis involved a review of the data for each case across all codes and a comparison within and across each case (parents, nurses, and physician). [41] The findings were then presented within the components of the Ottawa Decision Support Framework: client and provider sociodemographic and clinical characteristics, perceptions of the decisions, perceptions of important others about the decisions; and personal and external resources used to make the decisions.

The Case

Client's and Practitioner’s Sociodemographic and Clinical Characteristics

The parents are a middle-income, African American married couple in their late 30s who were expecting their first child together. The mother, Susan, has a school aged child from a former relationship and the father, John, was a first time father. Susan had been hospitalized briefly at 19 weeks for placement of a rescue cervical cerclage. Prior to the current hospitalization at 22 4/7 weeks, Susan had a bloody and watery discharge and was advised by a nurse to go to the emergency room. Upon admission to the hospital, she was noted to have premature rupture of membranes and cervical dilation. Despite attempts to maintain the pregnancy with bed rest in the hospital, the infant was stillborn at 23 3/7 weeks and weighed 480 grams.

For this case, the other participants included an MFM, NNP, and RN. The MFM was male and the RN and NNP were female. The MFM and NNP identified themselves as Caucasian and Methodist. The RN identified herself as Asian and Buddhist. All three worked full-time and reported having practiced in their current specializations for 20 years.

Client's and Practitioner's Perception of the Decision

Client’s and practitioner’s perceptions of the decision encompass the knowledge, expectations, values and decisional conflict each brings to the decisions to be made. [40] Susan was knowledgeable about and grateful for the treatment options presented to her which included: maintaining or interrupting her pregnancy, removal of cerclage, bed rest with hospitalization, or bed rest at home. She understood the predicted morbidity and mortality of infants at premature gestational ages, and relayed that if her infant survived he or she, “would not be able to learn as quick as the other kids.” The NNP described the morbidity and mortality information she gave to Susan using the following terminology: cerebral palsy, developmental delays, visual problems, prolonged hospitalization, and 50% survival at 24 weeks. According to Susan, the physician told her that her infant would not be resuscitated until 24 to 25 weeks gestation when the infant would be viable. Susan was hopeful she would make it to that point and was certain about her decision to keep the cerclage in and remain in the hospital on bed rest. According to Susan:

> I am 22-1/2 weeks, which is 22 weeks and 4 days. So, they were asking me….I can either terminate the pregnancy or try to hold out until I am at least 24 weeks that way the baby can have like a 20% to 30% chance to make it….If the baby does make it, the baby still might have major problems. I told them I understand that and that I may be at risk of having some kind of infection….I’m 10 days from being at 24 weeks, so I am going to try my best to hold out. So, hopefully everything will work out for me.

John did not remember that the physicians offered treatment options when Susan was admitted to the hospital, but he recalled that the physicians talked about the rupture of membranes and that they were sorry this had happened. Hearing this, John thought, “So it was kind of like the pregnancy was over then.” Susan had relayed to John the options she was given; he also wanted to give their infant a chance. However, while trying to be supportive he also viewed himself as being realistic:

> I wouldn’t say that I am not as positive as her, but I am a little more realistic than her and I see things the way they are and I don’t try to change them, so I am a little different from her and also too she has the baby in her. So, she feels more attachment to the baby than me by it being a part of her body.

John knew that if their infant was born at this early gestation, the lungs would not be developed. He felt that the subsequent 10 days were critical based on how Susan’s body responded and that nothing else could be done that would matter.

The physician described the options that he presented to Susan and said that termination limits and gestational age influenced his advice. On several occasions, the physician tried to explain to Susan that removing the cerclage may help to keep the pregnancy longer, and that everybody’s goal was to delay the birth of the infant for as long as possible. He explained how he thinks parents view that decision despite the risk for infection that the cerclage poses:

> I think she just had a gut feeling that it was going to be safer to hold the baby in with the cerclage and I am not sure, you know, I am not sure if I can ever explain that that way. The patients that counter intuitive could be very ingrained and it is just something these patients may not be able to intellectually overcome their gut feeling of holding the baby.

Client's and Practitioner’s Perceptions of Important Others Regarding the Decision

The perceptions of important others refer to the norms, perceptions of pressure, support from others and decision participation roles for clients and providers [40]. Susan reported that she and John were the ones most responsible for decisions and both felt this was the right approach for them. Susan relayed that physicians made her realize she was in charge and she felt respected because they gave her choices and listened to her. Susan felt that although it was somewhat of a shared process with the physician, the parent should have more input into the decisions, “I think the patient should have more say because it is actually the patient that is going through whatever, but is good to hear the doctor’s opinion as well.”

John was there to support whatever Susan wanted to do because she was the one carrying the infant, and would be more greatly impacted by the outcome. In addition, according to John, Susan told him, “I know you blame me, it’s my fault.”John explained that he did not blame Susan and that it was not her fault but was now up to God. When asked about shared decision making with the physician, John said it depends on how well you know, trust and respect the physician and their recommendations. He felt that the physician should give a recommendation and inform parents about all possible options, but that it should be up to the parents to make the final decision.

According to the physician, Susan had options regarding maintaining or interrupting the pregnancy and whether to remove the cerclage. He told Susan that he would support her decision, saying, “this is as much your decision as anybody’s, then I’ll support you with whichever decision you make [cerclage or termination]…because we think these are all your decisions at this point”. Because of the potential for disability in the infant, the physician left the decision up to the parents. There were six entries in Susan’s medical record that corroborated the physician’s and parent’s reports regarding treatment options and decisions.

The physician was not aware if John was involved, but did advise Susan to wait to make a decision until she could talk to a family member. When asked how parents want to be involved, the physician indicated that it varies and some parents want to be told what to do. He explained that he offers the same options to all patients regardless of whether or not they want to be involved in decision making. He said, “…and of course I don’t yell at patients or badger them if they don’t want to hear about it, but even if they want me to make the final decision, I still go through the same process of counseling.”

The NNP and RN did not ask Susan to make decisions but were there to provide information and reinforce the information that the physicians gave. According to the NNP, shared decision making between the obstetrical or maternal-fetal medicine physician and parent is the best approach, with a consultation from a neonatologist if the dates are in question. In this case, the NNP felt that the physician was most responsible for the decisions, which is in contrast to what the parents perceived.

According to Susan, her family was there to pray and provide support but not advice. John, however, reported that his mother-in-law was offering advice based on an experience with a family member. John felt that this was not helpful for Susan as the circumstances in their relative's pregnancy were different as their relative was almost full term. He said:

Her mother went through a thing, and she called up there this morning. I guess she felt that they should have delivered the baby right away once the water bag had broken, because something like that that happened to her sister, and that is what they did…and I told her mother, kind of told her, just "don't do that."

Client's and Practitioner's Resources to Make the Decision

Resources refer to personal and external resources, such as experience, self-efficacy, skills, motivation and other resources. [40] According to Susan, before coming into the hospital she knew nothing about extremely premature infants, except that her sister had had a perinatal loss at five months gestation and a family member of John's was born three months prematurely. John's family member was now reported to be a healthy adult.

Throughout their interviews Susan and John repeatedly stressed the importance of clear communication. This theme resonated both in how they described the care they received and in the advice they gave for health care providers and other parents. According to Susan there was one nurse who was really supportive and helped her understand information during an ultrasound. Susan said it was helpful that the health care providers translated medical terminology into words she could understand. She also appreciated health care providers' honesty and felt that they were telling her all of the information she needed about the prognosis without making her situation appear worse or better than it was. According to Susan:

> They told me, whatever question I asked, they cleared everything up for me and every time they explained they were like, "it is still not a guarantee" and I was like "I understand that." It is a risk and I understand that, so whenever they tell me ,"there is not a definite answer, nobody knows" but they made sure that they did not make a definite answer, and then OK something goes wrong, so that I could not come back and say "Now, you told me this."They made sure that they did not answer like that and I understand that, I really do, so I felt better about that because some people do say what you want to hear, they did not do me like that, so I really appreciate the honesty.

Both parents stressed the need for information to enable parents to make decisions and be more prepared to deal with an adverse infant outcome, including infant morbidity. According to John:

> Once again, I'll just try to say no matter how hard it is, give them [the parents] all the information whether good or bad. Just always make sure you let them know. Give them all the options and from there support them and let them make their own decisions, from there you should be all right as far as whatever issues come up.

John also talked about the compassionate care he received from one physician. While he could not fully describe what she did, but he felt it in their interaction. John said, "I could just feel it, in other words it was nothing that she really did. She said she was sorry and everything about the bag bursting and asked what happened…But I could just tell that she cared." John relayed that different people may need different things, like counseling from a professional, or a friend to talk to.

The health care professionals in this case also described the importance of compassionate care and giving information to this family. The nurse described these aspects of care when recalling her first encounter with Susan:

> I brought her to the room I introduced myself to her who I am and we talked and she respond to me and I told her that since she was having the cramping, I was going to give her some IV fluids to help her and also she is going to feel better with the cramp, and I told her that I said if you want to say anything, to talk, anything, she can talk to me or if you want to see the doctor, I can get the doctor to talk to her. So, I also listened to her and I told her that whatever she wants to do, I will give her the support.

This nurse also provided information and was encouraging to Susan while offering her a memento during an ultrasound.

> At that time, when I put the baby on the cardio [monitor] and we heard the baby's heartbeats and she was saying that she said, 'Yeah, that's the baby's heartbeat,' I said, 'Yeah, if you want to keep these, you can keep it. You have tried the best you could.' So, I didn't mention anything else and she didn't say anything else in a negative way on that day.

The nurse relayed how, at a later point, she visited Susan even though she was not assigned to her care. She said:

> That morning, I wasn't her nurse, but the way when I heard that, I knew that something was going to happen. So, I was just with her just for a few minutes and I just told her that, I said if you need help, you need me, you need anybody just let us know, we are here.

Thus, this nurse was a consistent source of support and information for this mother throughout the hospitalization.

The NNP had very specific advice for informing parents. Her advice included: giving parents and family members a tour of the neonatal intensive care unit, having a specialist (neonatal care professional) counsel parents prenatally, and being very prepared with specific morbidity and mortality outcome data before seeing the parents. Regarding the tour, she said, "I try to always encourage the family members and mother, if she is able to get out of the bed, to come and see…what a baby that size looks like and I think that is somewhat helpful." Conversely, the physician cautioned about giving too much information to parents but instead stressed the importance of developing a relationship with the parents and not rushing their decision:

> I would like to say more and more information, but that doesn't always help…. I know one thing, and I am 100% sure that developing a relationship quickly with a patient is important. Developing trust with a patient is important because they don't want to hear anything from you if you don't have that. I think empathizing is extremely important and expressing that, but these are obvious to me, but you have to create a therapeutic relationship….this is what it is all about….I think unrushed, you can't be rushed and I think maybe whoever talked to you about doing this in the middle of the night or early in the morning, that is okay, you have to talk and make some decisions perhaps, but it is time to back off then and let it settle, so I think re-visiting is important.

Thus, this physician recognized the importance of giving parents time to process the information and think through the decision.

Discussion

These parents faced various physical and emotional issues throughout Susan's brief hospitalization. Complications in this pregnancy included early second trimester cervical insufficiency. Cervical insufficiency is a relevant factor in preterm birth, whose cause and mechanism of onset are poorly understood. 43 At 19 5/7 weeks of gestation a cerclage was placed secondary to an acute episode of cervical insufficiency. Surgical placement of a cervical cerclage (a surgical procedure that closes the cervical os) is the standard treatment.[44] Postoperative complications of this procedure include extremely preterm prolonged rupture of amniotic members (EPPROM) and chorioamnionitis. 43

Prior to 24 weeks gestation, Susan experienced EPPROM. While the time from EPPROM to delivery is unpredictable and highly variable, in Susan's case the baby was stillborn soon after her membranes ruptured. Once EPPROM occurs with a cerclage in place there are several options. [45] First, is to remove the cervical cerclage, with subsequent termination or planned expectant management during the latency period (which includes possible spontaneous labor). The other options are to keep the cerclage in place with expectant management at home until pregnancy is viable, or management in the hospital. According to the parent and physician interviews in this case, Susan and John were informed of each of these options and they chose to manage her pregnancy inpatient and to leave the cerclage in place. For John, the rupture of membranes made him feel that the pregnancy may be over. The physician offered insight into the dilemma parents face when deciding about the maintenance or removal of a cerclage and noted that it seems counterintuitive that something meant to prolong pregnancy can also hasten delivery.

Despite John's feelings about the rupture of membranes, both parents were hopeful that Susan could make it to 24 weeks. Hope is increasingly recognized as an important issue for mothers at risk of delivering prematurely. The literature indicates that despite all of the uncertainty families face at this time, they struggle to remain positive and maintain a sense of hope. [46] As with Susan and John, spirituality and support from family may also help parents to cope at this difficult time. [47] In a study that explored the effects of high risk pregnancy on families, it was found that family support positively impacted mothers' ability to manage the current situation. [47] Although, sometimes families, in their attempt to be supportive, may say things that are not helpful. This was noted by John when he discussed his mother-in-law.

Although Susan and John expressed gratitude and were content with the type and quality of information they received, the issues that they presented are commensurate with those found in the literature. Parents often report the importance of being given as much information as possible in order for them to make an informed decision. [47–49] As indicated in this case, information goes beyond a discussion of morbidity and mortality. Parents want to be informed and involved in decisions made for themselves and their infants prenatally and postnatally. Even parents who do not want to make decisions on their own, as Susan and John did, will still need information, advice, and recommendations from physicians. [27, 28, 31, 33, 34] In addition, parents who prefer not to make decisions generally want to be included in discussions, receive information, and have their concerns understood by providers. [27, 36] In this case, the provider gave Susan options and reaffirmed that the decision was hers to make and he would support her with whichever option she choose. Both Susan and John described the importance of clear communication, and appreciated that her health care providers presented information in a clear and honest way by explaining medical terminology and giving her all of the information both good and bad.

In addition to the medical management, providers need to be aware of the other hardships these families face. For Susan she felt attached to her baby and yet she had no control over whether or not her pregnancy would end in loss. Being on bed rest may also contribute to a mother's stress as it decreases her personal autonomy and ability to care for herself. [48–51] According to John, Susan expressed feeling guilty over why this happened and feared he blamed her. While John in no way blamed Susan, feelings such as guilt and fear are common for women who experience a high-risk pregnancy and feelings of guilt may be further heightened if the pregnancy ends in a loss.[47, 48, 51, 52]

Caring and supportive behaviors from health care providers are essential at this critical time. Unfortunately, some women continue to report negative interactions with providers. [51] In this case, the interactions were positive and made an impact on Susan and John. Susan recounted that one nurse in particular was supportive and exhibited caring behaviors by helping her understand information. John explained that he felt supported by a physician in the way they interacted. In this case, the nurse made frequent overtures to the parents to listen and be there for them. She stopped by to see the mother even when she was not assigned to her, which demonstrated her genuine concern for this mother. Caring behaviors may also include providing information is several ways (written, video, internet), promoting family strengths by including other family members in discussions, and creating support groups for mothers who are hospitalized. [47, 48, 51]

Implications for Nursing Practice

The role of the nurse in the care of a woman who faces giving birth to an extremely premature infant cannot be understated. The nurse is at the bedside and is available for support and questions. For parents at risk of delivering extremely prematurely discussions about post delivery neonatal care options and palliative care can be initiated. The counseling may produce confusion and ambiguity for parents. While this is a very real and stressful event for parents, the physicians are talking about hypothetical situations and uncertainty. In addition, a mother's status can change quickly, so the information may change and it may be difficult to understand that the once hypothetical possibilities now present a real danger.

Given the confusion and stress that parents may be experiencing there are many things that providers need to consider. First, it is the parents who will have to accept the ramifications of their decisions for the rest of their lives. In addition, the management for pregnancies complicated by cervical insufficiency and EPPROM remains controversial and either option (to remove or maintain the cerclage) has risks for the mother and baby. Parents need to be counseled about the benefits and burdens of each intervention and it is often left to the nurse to make sure that the parents understand the information given to them. [53]

Fear of what may happen to the baby in terms of morbidity and suffering is often mixed with a fear of losing the baby. As a result, many women will wax and wane on their decision to continue the pregnancy. Good nursing care is especially important at this time as mothers may voice their ambiguity and fear to the person they feel most comfortable with which is often a nurse or nurse practitioner. They may reveal feelings and information they are afraid to tell their physician or partner for fear of what might happen. So the question becomes, what can nurses do to support decision making surrounding the anticipated birth of extremely premature infant?

Being Present When Information Is Presented

Ideally the nurse is present when the physician explains the medical implications of her condition and what those implications mean for her baby. This way the nurse can clarify and reinforce the information parents are given. Each option poses a trajectory that the nurse can help the parents foresee and consider. For example, it may be difficult for Susan to understand why removal of the cerclage may prolong the pregnancy, when the placement of the cerclage was for that very purpose. The nurse can reinforce and clarify her risks and options, and help her understand how quickly the situation can change. By being present when the information is given the nurse knows exactly what was said and can clarify questions. An assessment of understanding may be accomplished by asking the family to discuss what they understand about what is happening. By doing this, misinformation can then be corrected and further questions generated and addressed, thus allowing parents to make the best decision possible. [54]

Informing With Compassion

Prognostic information can be very frightening and difficult to hear, so the way in which the information is shared is critical. The nurse is mindful of the fragility of the mother's condition, both physiologically and psychologically and can assess the readiness of the mother and father to talk about decisions that may need to be made. Openness can be achieved through transparency by keeping the parents apprised of any changes, and providing rationale for the medical and nursing management. Morbidity and mortality data for both the mother and fetus should be given in a way that is understandable to parents. Information will probably need to be repeated several times before it is absorbed. [55] Written or video formats permit parents to re-visit the information and explain it to friends and family, if they choose. Parents want the truth to be shared in a hopeful way. The nurse in this case offered her presence, and the physician reinforced that this was the mother's decision to make. Thus, these providers gave Susan the message that they supported whatever decision she made.

The process of communication as well as the content sets the tone for the discussions with the parents. The nurse can reinforce information using the same language as the physician or explaining if the parents do not understand the terminology. Supplemental information may also be useful. Depending upon the protocol of the unit, the nurse may request a neonatal consultation so the parents' questions regarding resuscitation and care in the NICU can be addressed. A neonatologist or NNP will visit the parents, describe morbidity and mortality of infants born at various gestations, and describe the care the infant may receive in the delivery room and NICU. A tour of the NICU may also be recommended and has been shown to be beneficial. [56] For some units, though, only the physician can initiate a neonatal consultation, which may be a source of ethical distress for the antepartum nurses. The unit protocol may be that neonatology is not consulted until the mother reaches 24 0/7 days gestation. However, if the parents are seeking more information and want to speak to someone from the NICU there may be reasons to deviate from the customary unit practices. Nurses who believe the parents would benefit from a neonatal consultation should raise the issue with the attending perinatologist.

Advance Care Planning

While not described in this case, a Birth Plan provides a way for parents with a threatened preterm delivery to engage in advanced care planning for their baby. A birth plan allows parents to prepare for both a live birth and a stillbirth. [57] The plan is created to meet the needs of the baby and parents for whatever length of time the baby lives and is designed by the parents in partnership with the perinatal team. This plan affords parents the opportunity to live life with their baby to the fullest regardless of how short their baby's time with them is. [58] The Birth Plan covers such issues as how aggressive the resuscitation efforts should be, who should be present for the birth, what medications should be given, and whether or not the baby should receive feedings. [55]

If in place at an institution, a palliative care team can assist the parents in advance care planning for the birth of their extremely premature infant. The parents hope that the pregnancy will continue and that their baby will have improved chances for survival, but the team can assist them in developing a plan in case the baby is born too early and is not viable. It helps families to hope for the best but have a plan for the worst. [59] It is critical that information is given in a non-judgmental way. Parents have the right to choose for goals for their child goals that meet their family needs. This is when a palliative team approach can be beneficial. The team has a chaplain and social worker that can bring a different perspective to the family and can help them cope with their spiritual and psychosocial needs. [55]

Care After A Stillbirth

Despite the best care, adverse outcomes occur and should be anticipated. The parents need to be told of the possibility that the infant may die in utero or may not be viable at birth. The nurse can gently reinforce for the parents the possible trajectories and decisions to be made. While this case does not cover the end-of-life care and support Susan and John received, it is important for nurses who work with high-risk mothers to be aware of the meaning of this loss. A more thorough list of the effects of a loss due to stillbirth and nursing specific information may be found elsewhere.[52, 60–64]

Parents often need reassurance that they did nothing wrong and that they did not cause the stillbirth. Nurses can provide comfort by acknowledging their feelings and allowing them to articulate them. [62] The nurse should assess the parents for their interest and willingness to gather mementos and participate in rituals surrounding stillbirth. Not all parents will be able to participate, but their own way of grieving should be respected and supported. Practice guidelines for caring for bereaved families can be found at the Pregnancy Loss and Infant Death website (http://www.plida.org/w).

Memory making can be very important to these parents even when the baby is periviable. It is important to allow the parents to hold and interact with their baby in private and to allow them to engage in meaningful rituals. Individualized rituals allow families to create memories by saying goodbye to their baby while providing them with a place to openly express their grief. [63] Rituals may include bathing and dressing the baby, having the baby baptized, or having other family members present for a prayer. The nurse and palliative care team can assist parents by offering them the opportunity to hold the infant, take pictures, cut a lock of hair, and get footprints or hand impressions. [62]

The nursing unit may have a particular person or team who follows up with a call or visit to the parents after a period of time and assesses the need for grief counseling. With palliative care being relatively new in obstetrical and neonatal nursing, some units may involve the institution’s palliative care team or may have nurses or social workers who are experts in palliative care. The nurses should avail themselves of these resources both for the parents’ benefit and for their own benefit. Once discharged after the loss of their baby, a member of the bereavement team, or the palliative care team if they were involved with the family, should be designated for a planned follow-up call or visit. Prior to discharge the family should be given information about grief counselors or support groups. If appropriate and desired by the family, follow up cards can be sent on significant anniversaries.

Summary

The anticipated birth of an extremely premature infant poses many challenges for parents and health care professionals. Because parents are faced with difficult decisions that can have a long-term impact on the infant and family, it is critical to provide the type of information and support that parents need. Nurses are in a key position to meet the parents’ needs in this way and can make a profound difference in the way families experience this event.

Acknowledgments

The research described in this paper was supported by the National Institute of Nursing Research/National Institutes of Health, Grant # RO1 07904. Manuscript preparation was supported in part by the Center for Reducing Risks in Vulnerable Populations, Grant # P30 NR09014 and the Center for End-of-Life Transition Research, Grant # P30 NR010680, both funded by the National Institute of Nursing Research/National Institutes of Health.

The authors acknowledge the other research team members who include: Co-investigators Rama Bhat, MD; William Grobman, MD; Michael J. Hussey, MD; Sarah Kilpatrick, PhD, MD; Rob Kimura, MD; Raye-Anne de Regnier, MD; Howard Strassner, MD; and research specialists Michelle Huntley; RN; Ramkrishna Mehendale, PhD, MD; Dennie

Rogers, MD; and Lara Stein, RN. We are grateful to the couple who shared their story and to the physician and nurses who took the time to participate in this study.

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