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Parent Decision Making for Life Support Decisions for Extremely Premature Infants: From the Prenatal through End-of-Life Period

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Introduction

Most deaths of live born extremely premature infants (less than 25 weeks gestation) occur in the perinatal period,^{1, 2} which extends to the first week of life.³ Due to the high morbidity and mortality rate for extremely premature infants, many expectant parents are confronted during the prenatal period with the possibility that their infant may be too small for resuscitation to take place in the delivery room. Even when the infant survives, parents may be asked to withdraw life sustaining medical treatment, such as the removal of mechanical ventilation, within hours or days of the birth.^{4, 5} Although parental involvement in these life support decisions may be appropriate beginning in the prenatal period,^{6, 7} little research has actually been conducted that explores how parents are involved prenatally⁸⁻¹¹ or at the end-of-life.^{12, 13} In this paper, parent, nurse and physician perspectives regarding how parents make life support decisions for extremely premature infants from the prenatal through end-of-life period are presented. The data are from a study which examined parent, nurse and physician perspectives regarding the decision making and the decision support needs of parents making life support decisions for extremely premature infants.

Background Information

In general, parents want to participate in making life support decisions before and after birth of an extremely premature infant.¹⁴⁻¹⁹ The research on parental involvement in making perinatal life support decisions is limited and often focuses on who makes decisions, but not on how the decisions are made.⁸⁻¹¹ In a study of 26 mothers, Boss, Hutton, Sulpar, West and Donohue,²⁰ found that all of them wanted to participate in decision making about delivery room resuscitation for their infants. The mothers also reported that religion, spirituality and hope, and not discussions of morbidity and mortality, guided their decision making.

In a multi-center study exploring postnatal end-of-life decisions, McHaffie and colleagues interviewed 108 parents about their perceptions regarding withholding or withdrawing care from their infants.¹⁶⁻¹⁷ A majority of the parents wanted active involvement in making life support decisions, many viewing this as part of their parental obligation. Others have found that parents' may experience regret and feel burdened by making decisions about withdrawing medical treatments.²¹ Even when parents are not actively involved in decision making, they generally want to be present when life sustaining medical treatments are withdrawn from their infant.^{16-18, 22} However, some parents will not be able to watch their infant die.^{16-17, 23}

The relationship between parents and health care providers can impact parental decision making about their infant.^{16-17, 24-26} In addition, all parents need providers to address their parental wishes and concerns,^{14, 21, 27, 28} and to give them as much information as possible about their infant before and after birth.^{14, 29, 30} Several investigators have found that before parents will allow life-sustaining medical care to be withdrawn, they have to trust their physicians and believe that the infant's bleak prognosis is accurate.^{16-17, 24, 25} Nurses often play a special role in facilitating parent decision making by providing emotional support, helping parents understand information they are being told, and by attending to the physical care needs of the parents and infant.^{31, 32}

Methods

The Ottawa Decision Support Framework guided the larger study from which the five cases were drawn for this report.³¹ This framework was developed for client and provider decision making about treatment options for a variety of medical conditions.³³⁻³⁴ Data were collected and analyzed using a collective case study methodology. This approach is used to examine data from multiple participants for each case within a study in order to understand the complexity of interactions within each case and the interrelationships that exist among all of the cases.³⁵ Exploring parents' decision making from different perspectives allows for a richer understanding of the process that parents traverse. Finally, due to the sensitive nature of this research, successful measures used in prior research were enacted.^{36, 37}

Sample

In the larger study, a total of 40 cases were recruited from three hospitals. Recruitment occurred prenatally with women (and their partners) who were hospitalized and had been counseled about life support decisions because of the risk of giving birth to an infant before 25 weeks gestation. For this report, five cases were selected from the 40. In each of these cases, the infant was live born and died, and one parent had been interviewed prenatally and postnatally. These five cases are comprised of interviews with: five mothers, four physicians, three nurses, and one neonatal nurse practitioner. None of these fathers participated in postnatal interviews; thus only maternal interview data are presented.

Physicians were those who counseled parents about life support decisions, and nurses were identified by parents as those who clarified information about life support given by physicians.

Measures

The four semi-structured interview guides (prenatal, postnatal, stillbirth, and end of life) used were adapted from the Ottawa Decision Support Framework and worded differently for parents and health care providers. Information was gathered in the following areas: (a) client and provider sociodemographic and clinical characteristics (age, gender, clinical diagnosis and duration of condition); (b) perceptions of the decisions (parents' knowledge, expectations and values that impacted their decision making); (c) perceptions of important others about the decisions (individuals who were involved in making or influencing the decision including support from important others, family, and health care professionals); and (d) personal and external resources used to make the decisions (parents' previous experiences and access to external information). A medical chart form was used to collect maternal and infant medical information and to document discussions about life support decisions.

Data Collection

IRB approval was obtained and all study participants gave written, informed consent. All interviews were conducted in a private setting and digitally recorded. Mothers were interviewed prenatally and were contacted weekly until giving birth. Maternal postnatal interviews were conducted soon after birth and end-of-life interviews were conducted several weeks to months after the death depending on the mother's emotional readiness. Postnatal and end-of-life interviews were also conducted with health care providers, in person or via the telephone, several weeks after the death. Data collection was time intensive; there were 86 parent and 54 healthcare provider contacts needed to complete the 19 interviews.

Data Management and Analysis

The medical chart, demographic and interview data from five cases (a total of 19 interviews) are presented in this analysis. All interviews were transcribed verbatim, checked for accuracy, and coded based on the Ottawa Decision Support Framework and themes that emerged from the data. For each case, summaries and matrices were generated for prenatal, postnatal and end-of life interviews. The matrices allowed for comparison of data within and across cases and groups, i.e., parents, nurses and physicians.³⁸ All data were independently reviewed by two investigators (TM and KK) in order to identify and describe all of the themes within the framework.

Results

Sociodemographic and Clinical Characteristic

The mothers' mean age was 24.4 (± 4.93 years) with a mean education of 10 years (± 4.15 years). Four of the mothers identified themselves as Hispanic or Latino and one identified herself as Black or African American. Four of the mothers were single, and one mother was married. The health care professionals (five females and three males) had a mean age of 40.12 years (± 6.01 years) and the mean number of years in practice was 14.86 (± 7.95 years).

Except for the case of a mother who gave birth to triplets at 24 4/7 weeks gestation, all of the mothers gave birth between 23 and 23 5/7 weeks. Resuscitation was attempted for all of the infants. For the triplets, one died in the delivery room, the second died several hours later and the third lived for two days. In three other cases, the infants lived between a few hours

to two days. For the cases in which there was a death in the perinatal period, all mothers chose to hold their infant at the time of death. In the last case, the infant lived for almost six weeks before dying due to complications of extreme prematurity. This mother allowed ventilatory support to be withdrawn from the infant, but was not present when he died.

Perceptions of the Decisions

All mothers indicated that they wanted “everything done” for their infants in the delivery room. For one mother, this presented a challenge because even though the infant had a heart beat and was breathing, she was told that these infants do not usually survive. Despite the mother's insistence that the physicians do everything, she felt that they did not provide appropriate care, “It seemed like when they, they took her to the table to try, they put mask on her and they handed her back.” The mother lamented that the healthcare providers had not listened to her earlier on the day of the delivery because she had told them multiple times that something was wrong. All mothers continued to want “everything done” after the infant was born.

Mothers identified issues such as, pain and suffering and hope as impacting life support decisions. The desire to prevent suffering was explicitly described by four mothers. In two cases, the mothers cited a desire to ameliorate the infants' pain and suffering as a primary factor in their decisions to withdraw ventilatory support. According to one mother, “I just wanted the best for my daughter. I didn't want her to suffer anymore.” Another mother, after watching her daughter's behaviors, asked if the infant was in pain. In another case, it was the husband's view of suffering that largely determined the decision to withdraw mechanical ventilation.

Nurses and physicians also described the role of suffering in life support decisions. In one case, the nurse believed that the mother knew the infant would not survive and wanted to remove the ventilator in order to let the infant go peacefully. For the case with the triplets, the nurse thought that the parents decided to withdraw treatment since, “...after losing the other two...they witnessed the code on the second one and that they didn't want to do that again for this baby.” Physicians in two separate cases told mothers that their infants were suffering. One of these physicians told the mother and grandmother that they had done all they could and the infant was suffering. After the discussion, the mother and grandmother gave permission for the physician to remove the ventilator from the infant.

Two mothers mentioned hope with regard to decision-making and the infant's survival. In one case, hope that the infant would survive fueled the mother's determination to make physicians try and save the infant in the delivery room. While this mother thought there was less than a 1% chance that her daughter would live, she indicated that she had hope until the last moment. The mother of triplets reported feeling hopeful even after the first infant died because there were two who survived. However, after the second triplet died, she did not want her last infant to only live for a few weeks or months. She said, “since I already had to bury the other two...maybe I should let them all go together.” When interviewed after the deaths of her infants, the mother questioned the decision:

It is, you know, I sit here and try to reason with myself, you know, I am like well, you know, at least she went with her brother and her sister and on the other hand, it is like, you know, what if she was still here...So, if there is no way, I don't think to work around that because you are going to blame yourself regardless.

Perceptions of Important Others about the Decisions

All mothers reported being involved in making life support decisions for their infants and all of them received assistance to make the decision from their partner and/or family. Family

members included parents, siblings, aunts, cousins and friends. Three of the mothers reported making joint decisions with the infant's father. In two cases, important others had as much decision making responsibility as the mother. In another case, the mother's sister and mother encouraged her to "let God handle it" and said that the infant probably would not make it so the ventilator should be removed.

Nurses and physicians described the roles that parents, physicians, and family members had in making decisions. One of the nurses commented that while the physician gave all of the information and allowed the parents to make the end-of-life decisions, the physician was leading since the parents would not have spontaneously presented the idea of withdrawing treatment. Yet, for another case, the nurse said that the decision to withdraw life support was shared between the parents and the physician. In one case, the nurse practitioner said that the mother had a lot of family input and that the paternal grandmother seemed to understand that the infant's chances were poor. Three physicians described the role that family played in both decision making and in supporting the mother. In one case, the physician recalled that the mother wanted to wait for the father before making the decision to withdraw life support from the infant. In another case, the physician said that the mother received a lot of support from her mother, sister and brother-in-law and that her family was involved in making life support decisions.

Mothers described the importance of trust and communication as facets of their relationship with providers. One mother trusted her physicians and hoped that she had been given all of the information she needed to make a decision. In another case, the mother wished her own physician had been present because she did not trust "student physicians" and had not known the physician who delivered the infants long enough to build trust.

All mothers explicitly or implicitly discussed the importance of communication and receiving adequate information. Two mothers described wishing they had been given additional information prenatally. In some cases, the communication was positive. For example, mothers described how the nurses were not rushed and helped them to understand the information and also made them comfortable, which increased their ability to understand what they were being told. In others, the communication was distressing. For example, one mother received the physician's condolence even though her daughter was born alive:

...the doctor came in, I never had seen her before, it was a different doctor, and she checked me and right away she said, you know, that they were going to take me to delivering, but she told me, the thing that bothered me the most is that she told me I am sorry for your loss...before they checked her heartbeat...Before they took me to the delivery room and she kept telling me I am sorry, I am so very sorry for your loss and then they found that she had a heartbeat.

Another mother was angered when her explicit requests were not honored after her first two infants died. She asked not to be updated about her daughter's condition without her husband being present, yet the physician came in and, according to the mother, "I already knew it was bad news and it just really aggravated me."

The nurses described the information that parents were given by the physicians. In all five cases, the parents were given information about their infants' poor chances of survival. For the case with the triplets, the physician recalled that the mother thought that the infants had a fifty per cent chance of survival until he explained that it was lower for triplets. Another physician with this case, "tried to make the parents understand that it was not good for them or the infant to continue care because there was no chance for survival."

Nurses and physicians described the roles they played in preparing parents for the end of life. One nurse told the mother that she could hold the infant when the ventilator was removed. The nurse practitioner updated the mother as the infant's condition worsened and took the mother to the bedside when the infant was at the end of life. Physicians also played a role in supporting parents at the end of life. One of the physicians recalled telling the mother that they would not stop any treatments, but encouraged her to hold her son. This physician maintained the infant on life support so that the father, who was in heavy traffic, could see his infant alive. According to the physician:

I offered to her to hold the baby and she said I don't want to do anything that will quicken the baby's demise, that would make the baby die sooner. And I said I won't stop anything, you can just hold your baby, I won't stop any of the medications and I won't take out the breathing tube, you can just hold your baby and she said, so, so you won't, the baby won't die sooner. I said, well I don't think anything, I think your baby is dying now and I don't think your holding the baby will make anything go faster or slower. I promise I won't stop any medications.

Perceptions of Resources

All mothers described the importance of personal experience or external resources, such as media and the Internet. In one case, the mother's experience raising a foster daughter who was born preterm and a television show impacted the way she looked at the loss of her infant since, unlike the woman on the show, she would not have wanted her daughter to live only to die weeks later. For another mother, the information she gathered on the internet impacted her ability to hold out hope that her daughter would survive.

Discussion

Parental involvement in making life support decisions prenatally and postnatally is not well understood. The case study approach used in this research provided new insights and strengthened those previously recognized because it allowed multiple perspectives on perinatal parental decision-making to be explored. This study is unique because it used a case study approach to examine prenatal and postnatal parental decision making from multiple perspectives.

Parents articulated values that shaped their perceptions and decisions related to life-support for their infants. Several of the practitioners described the parents' wishes as wanting "everything done." Boss, et al.,²⁰ also found that health care providers often documented that parents "want everything done" when making decisions regarding delivery room resuscitation for high-risk newborns. In this study, all of the parents also used the phrase "everything done" to refer to their treatment wishes for their infants. While the concept of "everything done" was not explicitly defined by the practitioners or parents, it is an area that begs further research because the meaning of "everything done" may impact the mothers' perceptions of care. For example, in one case, when the mother asked that everything be done for her infant in the delivery room she felt that they did not provide appropriate care. Regardless of the actual care her infant received, this mother's expectations were not met.

The mothers also identified pain and suffering and hope as values that impacted decision making. Similar to the findings of Meert, Thurston and Sarniak,³⁹ several of the mothers in this study found that the amelioration of their infant's pain and suffering played a role in end-of-life decision making. Three mothers asked about their infant's suffering, and in two cases, the mothers explicitly described this as a factor in making end-of-life decisions. In several of the cases, physicians and nurses also felt that the parents' made decisions to withdraw medical treatments in order to end their infants' suffering.

Boss, et al.,²⁰ found that hope was one of the primary values that guided parental decision making regarding delivery room resuscitation for their high-risk newborn. Several mothers described hope as a factor in their decision making. One mother, despite knowing that her infant's chances were poor, maintained hope until the very last moment of her infant's life.

As seen in prior research,^{14, 16-19, 28} the mothers in this study wanted to be and were, involved in end-of-life decision making for their infants.^{14, 18, 22, 40, 41} Similar to the findings by McHaffie, et al.,^{16, 17} while a majority of the mothers in this study wanted to be present when their infant died, one mother was emotionally unable to be present. While two of the mothers described the difficulty in making end-of-life decisions, only one appeared to be burdened by being involved in decision making, which was a finding in another recent study.²¹

Despite mothers' roles in decision-making, importantly, these decisions were not made in by the mothers alone. Consistent with previous findings ^{11, 16, 17, 20, 42}, these mothers reported that friends and family often play a direct role in the mothers' and/or the parents' decision making. In the research reported here, family were involved in making life support decisions.

Consistent with previous findings,^{16, 17, 24-26} these mothers reported that their communication and relationship with providers impacted their experiences of decision making for their infants. For example, one mother who expressed a lack of trust in her physicians, also continued to question her decision when she was interviewed after the death. The mothers in this study, as found previously,^{14, 29, 30} articulated the significance of getting information. Several of the mothers wished they had been better informed by physicians. Several researchers have found that parents report that additional information from providers may have impacted or changed the decision the parents made.^{43, 44} The effect of additional information on their decisions is not clear.

Several of the mothers focused on how the information was presented which is similar to previous findings.^{17, 18, 24} The mothers reported both positive and negative communication with providers. In one case the mother felt that the nurses helped her understand information. Two mothers experienced negative communication with providers. In one case, the physician, without checking for a fetal heartbeat, told the mother he was sorry for her loss. In another, the mothers' express wishes to be left alone while her husband was gone were ignored. Both of these cases illustrate the importance of being sensitive to the experiences and requests of the mothers.

Conversely, as other researchers have found,⁸ providers often focused on the prognostic information that was given to the mothers. In the cases presented, most of the information focused on the infants' poor chances for survival. While none of the parents cited the prognostic information as impacting decision making, one of the nurses felt that the physician's presentation of this information was leading and may have affected decision making.

Providers also described their role in preparing mothers for the end of life once the decision had been made to withdraw ventilatory support. For example, several of the nurses and a physician encouraged the mother to be with and hold the infant at the end of life. As described previously, nurses often help parents prepare for the death of their infant throughout the dying process and at the end of life.^{31, 45} Additionally, Kavanaugh and colleagues³¹ found that nurses assisted parents in making life support decisions by providing physical and emotional support and helping parents understand information. According to Epstein,⁴⁵ nurses and physicians describe their experiences working with newborns and parents at the end of life as, 'creating the best possible experience' for

parents. In order to create this experience for parents, many providers described the following themes: building relationships, preparing for the end of life and creating memories.

Although none of the health care providers commented on parents' resources, all of the mothers mentioned the importance of personal experience and/or external resources. Two of the mothers discussed the role that the TV or internet played in their decision making. These examples illustrate the importance that the media can have on medical decision making and reifies the importance that both clinicians and researchers need to maintain an awareness of what external information parents are getting and how it affects them.

Limitations

While the analysis presented here offers insight into parents and life support decision making, there are limitations. The size of the sample drawn from the larger study is small, but includes an examination of the process that occurred over time. In addition, while the mothers in this study are all from minority racial or ethnic groups, the limited sample size does not allow for any comparison across the groups, or any speculation regarding how race and ethnicity impact decision making. Finally, while the Ottawa Decision Support Framework is a very useful way to look at decision making, it does not fully account for the importance of parents' perceptions about positive or negative communication with health care providers.

Implications

Parents generally, but not universally, want to be involved in making life support decisions. However, as the cases illustrate, parents need more than just information. Often their ability to be involved hinges on their relationship and communication with health care providers. Trust is an essential component of this relationship. High risk perinatal care delivered in Level III academic medical centers require a rotation of attending physicians, housestaff, medical students, and nurse practitioners. It can be confusing, overwhelming, and unsettling for parents to receive information, especially uneven information, from various individuals whom parents cannot place in the hierarchy. Often parents assume attending physicians have the greatest knowledge and experience, and physicians who are not attending physicians are students and still learning. It is important for fellows and residents to learn communication skills under close supervision and for nurses to be present during discussions to help clarify information.

Trust can also be built by admitting uncertainty. As with the use of the term “suffering”, health care providers may think they need to emphasize the worst case scenario should the infant survive so parents will find solace in choosing death as the least worst outcome. Health care providers should present data on survival and outcome with the ranges and statistics in an understandable way. They should also add that there is uncertainty in predicting outcomes, but these are the data on which clinical decisions are made. Nurses who were present at the discussion with parents could then clarify and reinforce the information as parents often needed to hear the information more than once. A consultation with a perinatal or pediatric palliative care service can assist the team members to guide parents through decision making, especially in those situations when the parents' requested goals for care are unclear to the team.⁴⁶⁻⁴⁹

Clearly, parents need information given in understandable terms, in a timely fashion, and with compassion. Parents often need information repeated; health care providers may start the conversation by asking parents what they understand about what they have already been told. Explaining terminology and preparing parents for what may happen next serves to keep

them oriented to the course of events as they unfold. Parents should be told, when possible, what decisions they need to contemplate and when a decision needs to be made. Prenatally the parents may be asked to consider forgoing resuscitation if the baby appears nonviable at birth, and the health care providers should describe what is meant by “nonviable”. The parents' decision may influence later clinical decisions, such as where the mother will deliver (labor room vs delivery room) and whether anyone from neonatology will be asked to attend the delivery. Gestures such as sitting at eye level with the parents, listening actively, consoling the parents on the difficult situation they are facing, and taking time to answer questions and assess their understanding demonstrate a caring attitude toward parents.

Offering information and providing the parents time to ask questions are essential when giving them large amounts of distressing information.⁵⁰ However, decisions often need to be made quickly without the luxury of time. In these instances, there are still steps that providers can take. For example, parents appreciate when providers demonstrate care and show concern while delivering information as opposed to dispassionately providing medical updates.⁵⁰ One of the most important elements when communicating distressing news is for providers to allow and encourage parents to have hope.⁵¹ Hope can be very powerful and provide a source of strength for parents even in the most dismal circumstances. Health care providers often avoid giving hope because they associate hope with intact survival or cure.⁵²⁻⁵³ Parents want their health care providers to be honest yet hopeful. Hope can be an elusive concept and a moving target. Parents initially hope the premature delivery will not happen, or when born, the preterm infant will be healthier than expected. When those hopes are dashed, they hope that more can be done, or finally that the infant will not suffer. Health care providers can maintain the parents' hope without feeling dishonest or misleading. Information should be shared in a way that forecasts the possibilities, identifies the options, and facilitates decision-making. Parents may want another source of information such as a second opinion (e.g., a neonatal consult).

Additionally, parents may not have a clear understanding of the events leading to the infant's death. This emphasizes the importance of a follow-up meeting between the parents and the physician in order to clarify events and discussions that occurred prior to death of their infant. The medical centers in which this study was conducted varied in their resources for palliative care in the NICU. All had policies and practices for grief and bereavement. None had a palliative care program for NICU although one institution was considering it. Refocusing the goals to prioritize infant comfort provides parents with the sense that everything is still being done to achieve the treatment goals. Parents do not want to feel that they gave up on their infant.

As illustrated above, there are many factors that appear to influence mothers' end-of-life decision making. An extremely compelling factor in parents' decision to withhold or withdraw life sustaining treatment rests on the perception of the infant's pain and suffering, whether current or future. Health care providers should acknowledge the power they have to sway parents' decision by characterizing the infant as suffering, or predicting the infant will suffer. Attention to pain management has been greatly improved over the years, so an infant's pain should be relieved. The extent of infant suffering is not perceptible. The existential suffering of the parents, extended family, and health care providers is often acute and through projection, may contribute to the impression of the infant suffering. Health care providers should be mindful of the power in the word “suffering”.

Partners and family members are also affected by the decisions and they not only support the mother, but they are often instrumental in helping her to make life support decisions. While many providers try to include family members in discussions, they need to explicitly ask and

respect the parents' wishes regarding who should be present. It is equally as important to respect their wishes if she requests that family members be excluded from conversations. Healthcare providers can ask the parents if their family members have the resources to come to the hospital, and if they do not, the staff should look into facilitating travel options.

Finally, the significance of external resources should not be overlooked. Recent years have ushered in a proliferation of television shows and Internet websites about premature babies who survive under extreme circumstances. It may be confusing or frustrating for parents who avail themselves of these media sources to understand why their infant did not survive, or why there is nothing more than can be done. Nurses and other healthcare providers should actively try to keep current on commonly available media and should anticipate and be prepared to answer questions that may arise.

For further research, it is imperative that scholars begin to explore: (1) the decision making process; (2) what factors parents rely upon to make life support decisions for their infants; (3) the role that fathers and extended family play in decision making; and, (4) what health care providers can do to aid and support the parents. The results presented here can serve as a catalyst for future research on parental life support decision making for their infants.

Conclusion

Life support decisions are among the most difficult parents will ever face. More research is needed in order to inform healthcare providers about how to best provide support and care to parents making life support decisions for their infant. Future research should address issues such as, how much parents want to be involved in decision making and how to clarify and determine the roles of parents and health care providers in making life support decisions. While these decisions will never be easy or pain free, there are many things that health care providers can do to support parents.

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