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Divergent Views of Hope Influencing Communications Between Parents and Hospital Providers

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Abstract

This study evaluates parents' and health care providers' (HCPs) descriptions of hope following counseling of parents at risk of delivering an extremely premature infant. Data came from a longitudinal multiple case study investigation that examined the decision-making and support needs of 40 families and their providers. Semi-structured interviews were conducted before and after delivery. Divergent viewpoints of hope were found between parents and many HCPs and were subsequently coded using content analysis. Parents relied on hope as an emotional motivator, whereas most HCPs described parents' notions of hope as out of touch with reality. Parents perceived that such divergent beliefs about the role of hope negatively shaped communicative interactions and reduced trust with some of their providers. A deeper understanding of how varying views of hope might shape communications will uncover future research questions and lead to theory-based interventions aimed at improving the process of discussing difficult news with parents.

Keywords

communication; medical; content analysis; culture/cultural competence; decision making; disability/disabled persons; end-of-life-issues; infants; high-risk; parenting; pregnancy; high-risk; relationships; health care

Health care providers (HCPs) are responsible for discussing the treatment options and the potential health outcomes with parents when parents are at risk of having an extremely premature infant (22 to 25 weeks gestation or also called a periviable delivery). The outcomes in extremely premature infants are variable, imprecise (Ho & Saigal, 2005; Marlow, Wolke, Bracewell, & Samara, 2005; Stoll et al., 2010), and also culturally bound. (Blanco, Suresh, Howard, & Soll, 2005; Donohue, Maurin, Kimzey, Allen, & Strobino, 2008; Janvier, Leblanc, & Barrington, 2008; Oei, Askie, Tobiansky, & Lui, 2000). Hope has been defined as a positive outlook toward a desired future outcome (Scioli, 2007). Beliefs

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about the role that hope plays for parents, during such discussions, might differ between HCPs and parents (Charchuk & Simpson, 2005; Meadow & Lantos, 2009). There is a growing body of literature espousing the benefits of HCPs expressing positive optimism when breaking bad news, especially when there is some uncertainty related to the prognosis (Boss, Hutton, Sulpar, West, & Donohue, 2008; Charchuk & Simpson, 2005; Miquel-Verges et al., 2009; Reder & Serwint, 2009). HCPs might intentionally or unintentionally tailor their behaviors and the information they communicate to parents based on their attitudes and beliefs about the infant’s or family’s outcomes (Apatira et al., 2008).

In pediatrics, investigators have reported that hope can help parents to transcend the psychological impact of emotionally and spiritually devastating circumstances, find a protected place until they are ready to accept difficult information, and make decisions during their child’s changing health condition (Charchuk & Simpson, 2005; Mack et al., 2007; Reder & Serwint, 2009). Conversely, parents describe a lack of hope, or their hope being taken away, as physically and psychologically draining (Charchuk & Simpson, 2005; Reder & Serwint, 2009; Roscigno & Swanson, 2011). In one study, investigators reported that parents of children with cancer found hope in the full disclosure of prognostic and treatment information, even when their child’s outcome was grim (Mack et al., 2007). Thus, it is possible for parents to have both a realistic understanding of prognosis, even when it seems grim, and simultaneously maintain hope. Reder and Serwint also reported that the parents in their study felt compelled to maintain hope for their children’s future.

In this article, we report our findings related to the varying notions of hope between parents who were at risk of a periviable delivery and their HCPs. These data come from a larger multiple case study investigation that examined prenatal and postnatal decision-making of parents regarding treatment decisions for extremely premature infants. Despite a basic understanding that hope can be important to parents, knowledge of varying stakeholder’s viewpoints in the setting of extremely premature births is not fully understood or considered. A deeper understanding of parents’ expectations regarding information sharing and how differing beliefs about the role of hope might affect parent/provider interactions will provide critical input for future research questions. This knowledge might also challenge our theoretical understanding of the process of discussing difficult news with parents and the outcomes of not considering the parents’ point of view.

Methods

Participants

We maintained Institutional Review Board (IRB) approval at each of the three Midwest urban hospitals in the United States with level three neonatal intensive care units (NICUs). A total of 40 women, who were hospitalized for a threatened preterm delivery before 26 weeks, 14 of their partners, and 71 HCPs (physicians, neonatal nurse practitioners (NNPs), and staff nurses) were recruited and gave their consent to participate between April 2005 and September 2008. Expectant parents were eligible for inclusion if they were English speaking, at least 18 years of age, and had participated in a prenatal discussion with a physician regarding treatment decisions for their infant because of threatened preterm delivery (22 0/7 to 25 6/7 weeks gestation). A total of 21 fathers met eligibility criteria for the study, 14 of whom also agreed to be interviewed. Participating HCPs were identified by parents as those who had spoken to them about the life-support treatment decisions for the infant or had helped to clarify information given in counseling. Recruitment of any parents started after a research specialist at the hospital obtained the mother’s permission to be contacted by a member of the research team. A total of 63 women were approached and 50 agreed to participate. However, only 40 of the 50 women were successfully enrolled. The remaining 10 women became clinically unstable or gave birth before the initial interview could be conducted.

Data Collection

All participants were interviewed longitudinally, beginning in the prenatal period and extending into the postnatal period. A total of 203 interviews were done (137 prenatal, 51 postnatal, and 15 end-of-life interviews). There were four types of semi-structured interview guides used for the study (prenatal, postnatal, stillbirth, and postnatal end-of-life). Guides were worded differently depending on whether the interview was with a parent(s) or HCP. The content of the interview guides was based on the Ottawa Decision Support Framework (O’Connor et al., 1998) and designed to elicit: (a) parent and provider socio-demographic and clinical characteristics; (b) perceptions of the decisions (e.g., parent knowledge of the health care condition; information that was given/explained to parents by physicians and nurses, as well as parent evaluation of the way in which it was given); (c) perceptions of important roles of others (e.g., decision roles of parents, family, and health care professionals); and (d) personal and external resources used to make the decisions (e.g., support from physicians, nurses and others to make the decisions; skills; and advice for others in similar situations). Notions of hope or false hope were primarily spontaneously generated by participants in their: responses to questions about the information that was given or explained; their evaluation of the way in which it was given; and their advice for others. Additional probing questions were asked to understand the ways in which each group saw hope positively or negatively playing a role in their communication interactions.

Most parents chose to be interviewed on the same day they gave informed consent. Mothers and fathers were offered the option of being interviewed separately. Physician and nurse interviews were conducted separately from the parent(s) and as soon as possible after the mother’s interview. All of the interviews were conducted in a private setting, audio recorded, and they typically lasted between 30 to 45 minutes. The parent(s) and any HCPs for each case were interviewed by different investigative team members as a means of protecting each participant’s confidentiality.

Postnatal interviews with parents were conducted regardless of infant outcome to determine if there were additional discussions with HCPs about life-support decisions that occurred after the prenatal interview. These interviews also allowed parents to add their retrospective accounts of encounters up to that point in time. Postnatal interviews were also conducted with the physicians and nurses who participated in discussions about life-support decisions after the infant’s birth. When an infant was born between 22 and 25 weeks of gestation and survived, mothers and physicians were contacted weekly regarding ongoing treatment decisions. Weekly contact continued for the first 28 days of life or until two months of age depending on the infant’s condition. Subsequent postnatal interviews were done if there were any changes in life-support decisions or if the infant died. Parents of infants who were stillborn were contacted at least three weeks after the birth and asked to participate in a postnatal interview. When there was a neonatal death, separate interviews were conducted with parents and any HCPs at least three weeks after the loss.

Data Analysis

All interviews were originally transcribed verbatim, checked for accuracy, and coded in Atlas.ti 5.7.1 program (2010). Our team members developed a list of general codes after conducting preliminary data analysis. The original agreement regarding the assigned codes was established by two independent coders overlapping with 45 percent of the same transcripts. Team members met to discuss any coding inconsistencies. Participants’ narrative data and investigators’ field notes were used as the primary source to support or refute any conclusions. A code-based descriptive case summary was then prepared for each research participant. From these summaries, matrices were constructed for each of the four types of interviews (prenatal, postnatal, and end-of -life), allowing for comparison of data within and across cases (Miles & Huberman, 1994). The matrices displayed thematically coded data stratified by parent, physician, and nurse interviews.

Following the original coding, we recognized intriguing patterns of divergent conceptualizations of hope between parents and many HCPs. In many cases, parents' descriptions of the communicative setting, strong word choices, rhetorical tone of their responses to experiences, and descriptions of how they felt following these interactions revealed the importance of how beliefs about hope affected communication in this context. A focused analysis of hope was warranted to fully explain the divergent cultures under which this group of stakeholders conceptualized hope and entered into these conversations (Hinds, 1997). This rich contextual information was critical to understanding how the socio-cultural environment might also influence parents' experiences, decisions, and meaning.

All instances in which parents and providers described the following were included in this analysis: (a) the word "hope"; (b) the notion of positive optimism or an optimistic outlook toward the future; (c) the words "false hope"; or (d) the notion of a pessimistic outlook toward the future. These narratives were found within four of the originally coded categories: (a) hope; (b) quality and support in interactions with HCPs; (c) advice for support; and (d) experience and internal resources.

Content analysis was the approach used in this analysis. It is a rigorous qualitative research methodology that can be used to evaluate narrative textual data (Holsti, 1969). This secondary analysis of the divergent notions of hope was determined by us to be congruent with the original: (a) aim of the study to understand the decision-making process between parents and HCPs (Szabo & Strang, 1997); (b) sample selection criteria (English speaking parents at risk for delivering prior to 25 weeks); and (c) the methodology used to gather the accounts (open-ended, semi-structured interviews with a case-study approach) (Szabo & Strang, 1997). Three of the investigators who were actively involved in this secondary analysis process had conducted the original interviews and data coding. Therefore, we were also able to ensure that the context of the data was not lost by only analyzing a portion of the interview data (Hinds, 1997; Morse & Field, 1995; Szabo & Strang, 1997).

Two team members first independently coded the data from the four categories (Roscigno and Kavanaugh). One of these team members was the primary investigator (Kavanaugh), who had conducted many of the interviews, and was very familiar with the context of the entire dataset. Both coders had accessibility to the entire set of interviews, field notes, and summary matrices so they could validate or check their hunches against overall context (Hinds, 1997; Morse & Field, 1995). These coders then met regularly to discuss their coding and when discrepancies were found. Each coder provided narrative examples or contextual information (e.g., field notes, other interview data, or matrix summaries) to support conclusions (Szabo & Strang, 1997). The subthemes of hope generated by these two coders were then shared with two other team members (Savage and Moro), who also had interviewed many of the participants and originally coded the entire dataset. This allowed the investigative team to ensure that their hope subthemes were not taken out of context from the entire data set (Thorne & Morse, 1994). Additional co-investigators (Kilpatrick, Strassner, Grobman, and Kimura) were physicians known to the study participants and were prevented from having access to any interview transcripts to protect confidentiality of participants. They were able to comment on the summary matrices (within and across analysis), the clinical relevancy of the resulting themes, and contribute to the final manuscript.

The rigor of this analysis process was maintained by using several techniques: (a) participants' descriptions were the primary source of data from which any conclusions were made; (b) an audit trail was maintained throughout; and (c) peer debriefing helped to ensure that transparency was maintained, findings maintained fidelity to participants' overall narratives, and they were agreed to be clinically relevant to this setting and presented fairly (Lincoln & Guba, 1985; Ryan-Nicholls & Will, 2009).

Results

Parent participants (n = 40 mothers and 14 fathers) described themselves as primarily Black (n = 31) or Hispanic (n = 15) and ranged in age: M = 29 years of age (SD = 7. 3). Parents reported their years of education as M = 12.8 (SD = 4.09) and marital status as married (n = 20); single (n = 16); or single and living with a partner (n = 15). Yearly incomes were reported as: < $5,000 ($n$ = 5); $5,000 – $10,000 ($n$ = 5); $10,001 – $24,999 ($n$ = 3); $25,000 – $29,999 ($n$ = 6); $30,000 – $50,000 ($n$ = 11); $50,001 – $70,000 ($n$ = 7); $70.000 – $90,000 ($n$ = 2); > $90,000 ($n$ = 8); and, income not reported (n = 7). The most prevalent religions reported were Protestant (n = 30) and Roman Catholic (n = 15), but nine parents did not report a religious affiliation. Mothers were enrolled at the following weeks of gestation: 21 to 21 6/7 (n = 1); 22 to 22 6/7 (n = 12); 23 to 23 6/7 (n = 12); 24 to 24 6/7 (n = 11); 25 to 25 6/7 (n = 4). A total of 46 infants were born, which included two sets of twins and two sets of triplets. Seven infants were stillborn and 10, including two sets of twins and one set of triplets, died during the study. The mothers for all 40 cases gave birth at the following weeks of gestation: 22 to 22 6/7 (n = 2); 23 to 23 6/7 (n =11); 24 to 24 6/7 (n = 7); 25 to 25 6/7 (n = 7); ≥ 26 (n = 11); unknown (n = 2).

Participants who were HCPs consisted of staff nurses (n = 23) and NNPs (n = 6) (henceforth referred to together as the nurse group) and physicians (n = 42). The nurse group were all women and reported M = 15.6 years in the profession (SD = 9.7), whereas the physician group included 24 women and reported M = 14.0 years in the profession (SD = 11.2). The nurse group was primarily White (n = 21) and Black (n = 4) and M = 39.4 years of age (SD = 10.0), whereas the physician group was primarily White (n = 18) and Asian (n = 15) and M = 41.6 years of age (SD = 10.6).

Parents' Themes

The five main hope related themes described by parents were: (a) needing to hear the full range of information; (b) needing to know that every chance is given; (c) holding on to hope; (d) experiencing a different reality than anticipated from HCPs' predictions; and (e) relying on spirituality.

Needing to hear the full range of information—Most parents wanted to hear the full range of treatment options and possible outcomes during the prenatal counseling sessions. They wanted negative statistical information to be tempered with hope. "Like you can give the negative side so they know what they are in for, but don't just leave it negative." Parents expressed the emotional motivation that balanced information meant to them in their prenatal interview:

> When you hear negative, and you don't hear no success stories it kind of discourages you from trying to hang in there. I wish that success stories would be shared if any exist. You know … it makes you want to try to hang in there instead of just all the bad.

The parents who perceived that their counseling session and any other interactions were overwhelmingly negative believed that HCPs wanted to persuade, scare, or intimidate them.

Several parents criticized the communicative setting created when sharing prognostic information (i.e., the words chosen, the tone of the discussion, the body language, the sensitivity of the HCP to the parents' goals, the opportunity to have information explained in fuller detail, and the unwillingness of some to share stories of positive experiences or possibilities):

> It was a rough week because their attitude to me was … "Do you want to go home with just anything?"…. "You know it won't be viable, so are you just going to allow it to die?" [They said] "Now, we can do all we can, but you will go home with just anything." And I thought that was a little harsh to say, you know, "just anything"…. What they meant was did I just want to come home with a baby that possibly was blind, deaf, [or had] cerebral palsy, just no life value and they called it "anything"…. I thought it was pretty bad.

The balancing of information and a confirmation of a shared goal toward a possible good family outcome was reported as what parents needed:

> A lot of doctors told us, they were like … they were very supportive and very hopeful. They would tell me you know the risks and everything that can happen you know and it does sound kind of negative, but then right afterwards they tell me you know "We are hoping everything is good"…. So as long as you have hope and as long as you know you are not thinking negatively…. That is how I got through it.

Parents reported they were not apt to trust providers if they believed they were not given the full range of possibilities. Parents' responses to perceived negative counseling interactions suggested that they did not always respond positively, either emotionally or in their subsequent decisions, to advice that they perceived was framed primarily toward the negative. Parents noted that these interactions were likely to lead to them to discount the advice they were given:

> When I first came to the emergency room, which was Friday, they told me I had a week left to decide [if I was going to terminate my pregnancy]…. [Each day they would say] "Okay, what did you decide?" "Seven more, six more, five more [days left]." I went from five to one. What happened to the other days in between?…. So I think those are just bully tactics…. They want to tell you how they feel, without asking you how you feel…. When you're dealing with [an important decision, such as] termination [of your child] … that takes more than just a probability. If you're going to tell me to terminate, you need to give me some definitive proof, that there will be more harm than good that comes out at the end…. Your job is to give me the medical facts, to inform me to make my own decision. Your job is not to pound me. Your job is not to ponder me…. If I do not ask you about it any further, you need not tell me about it any further, because it's quite possible I have already made my mind up.

Needing to know that every chance is given—Many parents expressed a desire to have the HCPs attempt all realistic treatments. This wish was based on knowing the uncertainty in predicting long-term infant and family outcomes related to extremely premature infants. "To face that nothing could really be done and knowing I lost another child. That would be the most devastating part." Parents expressed relief following their prenatal interviews when they believed that every relevant treatment was being undertaken to improve their chances of maintaining their pregnancy longer and potentially having a healthy infant. They expressed anxiety when they perceived that HCPs' negative attitudes about the value of having a child born with disability potentially influenced the treatment options that they were offered:

> Like his doctor like “Okay, his lungs aren’t fully developed yet, but we are going to give him this shot to help develop his lungs and his brain [if he reaches 23 or 24 weeks gestation].” … There you got some hope, but if like, he probably won’t make it, then that is going to depress you even more. But you get some type of hope there, then you are like Okay, let’s hope this works.

Parents statements often suggested that parents did not always fully understand how dramatically infant development progresses from week to week and why some treatment options would not be warranted at one week in development, but suddenly warranted the following week. “They basically told me they wouldn’t be able to do anything for me at 22 weeks … but I was trying to figure out why they would do it at 23 weeks and not 22 weeks?” This type of confusion among parents highlighted that even if treatment information is explained to parents, it might not be understood and could affect how some parents interpret subsequent communication with HCPs.

Holding on to hope—According to many parents, having hope gave them the emotional energy to cope with recommended treatments meant to enhance the outcome of the mother’s pregnancy, to make plans for the birth of their baby, and to cope later in the NICU. For instance, the positive experience of reading a parent-written scrapbook available at one of the hospitals was seen as helpful by those parents while the mother was hospitalized and trying to maintain her pregnancy:

> I think the scrapbook is very good.… There was this one story, this young lady, her bag [of water] broke at 17 weeks, she was at home for seven weeks, in the hospital for three weeks, that was her twenty-seventh week and she was still pregnant. So you know, and it gave me a way of knowing that okay, then, I might just be able to carry this baby for another ten weeks.

Even when their infant died, in their end-of-life interviews, parents described the importance that hope played during the prenatal period in supporting them emotionally until the very end of their infant’s life. “There’s always the hope that maybe she was going to be the one [that beat the odds], you know. No matter what, I had that hope till the very last [moment].”

None of the parents discussed a negative impact from any HCP’s expressions of hope, although several said they did not want to be given false hope. Their descriptions allowed us to inductively derive a definition of false hope. False hope was information that was too optimistic and given simply to make the parent feel better at the time without also acknowledging or preparing the parent(s) for any potential negative outcomes. “I wouldn’t want to have false hope … that would be my biggest fear.… [Because then parents would] cling to the fact that you told them, you told me it was going to work out.” Inductively deriving parents’ conceptualizations of false hope helped to emphasize the importance of giving parents the full range of positive and negative potential outcome information.

Parents also talked about receiving information from many other resources outside their interactions with HCPs. Some of these resources included: past experience, trusted friends or family, magazines, television shows, the internet, and other parents who had been through similar experiences. According to parents, these resources further influenced how they contextualized and processed the information they received from HCPs. For instance, personal and family experiences sometimes countered what two parents were being told in their prenatal counseling session and affected their appraisal of the situation:

> Father: Now all I got to say, as living proof is our last son [was born] at seven months, and I got a sister … [that was born at] six months.… This is living proof; just because you are premature it doesn’t mean that you have brain damage.

> Mother: They say if you stay on oxygen too long that they could have damage to the brain. My son was on it for three months with no problems.

Potentially having a child with impairments did not automatically carry negative meaning for parents:

> And he [dad] works with kids with a lot of disabilities … and I have been around and I have seen them kids and even though the disabilities they got. If it was mine I still couldn't let them go, I mean, we has seen some kids with wheelchairs that have to be fed with tubes. I still say, that it is still your child. I know it is a lot to handle.

Experiencing a different reality than anticipated from HCPs' predictions—In seven cases, parents perceived that both the information they received and many of the subsequent interactions with HCPs had a very negative slant. These parents were very dissatisfied with their experiences interacting with HCPs, which in the interviews was made clear by their tone of speaking, the strong nature of the words they used to describe their interactions, and their rhetorical arguments of how things should be. Despite the dire information this subgroup of parents reported receiving about their infant's potential outcome, in five of these cases their infant survived delivery and was stable at one month of age (defined as requiring no ventilator assistance, no history of surgery, or no Grade III/IV intraventricular hemorrhage). Two of these seven mothers gave birth after 32 weeks gestation and one gave birth at 38 weeks gestation. This group of parents did not have the pregnancy or early-infant complications that they reported they had been warned about.

The discrepancy between the mothers' and infants' projected health conditions and their actual outcomes in the early postnatal period eroded parents' trust in their HCPs. When interviewed again postnatally, this group of parents expressed that they were fearful for other parents who might rely on negatively framed information alone to make decisions for an infant's and family's future. "You've got to be a strong enough woman or person to deal with it, because, a weak person, they'll buckle you at the knees." No parent in any of the 40 cases, including those with an infant death, reported that he or she was dissatisfied with receiving positively framed information in addition to potential complications.

For a small number of parents, their perception of the positioning or *anchoring* of information toward the negative was reported to affect their subsequent decisions in a way that was counterproductive for the mother's and child's health. For example, in two cases, the mothers left the hospital before delivery and against medical advice (AMA), and in a third case, the mother reported contemplating leaving AMA because of her experiences, but she ultimately decided not to leave. She later reported that she experienced emotional distress by staying and having to deal with encounters that she perceived as attempts to challenge the legitimacy of her decision. Others reported subsequently ignoring some information given to them by some HCPs.

Relying on spirituality—In prenatal and postnatal interviews, many of the parents described how they drew from their spirituality as a way to make meaning of their experiences. Several of the parents who believed that HCPs presented predominantly negative information reported relying on their faith and inner strength to maintain their hope. They felt that many of their interactions with HCPs were emotionally draining and negatively impacted their ability to cope and make decisions. "I would say don't believe everything that the doctors say.… It's in God's hands. I mean no matter what they tell [you]."

Many parents reported that their faith gave them hope despite all of the negative information they had received. "The Lord wouldn't allow me to get pregnant, after all these years, knowing something is going to go wrong. So I'm gonna hold on to that hope." Parents reported that during this tenuous time their faith or inner strength also helped them in future interactions with HCPs to hold on to their perspective and trust in their own decisions. Parents often stressed, however, the negative psychological impact that clashes in beliefs had on them over time: "You got to keep your faith because if you let somebody bring you down with the negativity, [it] is very hard. You [would … say forget this and just give up."

Health Care Provider Themes

Three main hope-related themes were found in the HCPs interviews, including: (a) relating hope to outcome; (b) being influenced by experiences; and (c) finding a balance between hope and false hope.

Relating hope to outcome—Many HCPs reported that giving hope was related to whether or not the child could survive or be born without disability. For some, this belief influenced the information they reported was stressed in the prenatal counseling session. In some cases, HCPs' views on hope also seemed to affect their willingness to accept the parents' depth of understanding. Many HCPs stated that parents did not understand the information being given to them and the future impact of having a child born with impairments. They believed that it was critical to help parents understand the potentially negative impact that having a child born with impairments might have on their future quality of life:

> But as far as I am concerned there is no good news in 23 to 24 and 25 weeks. Occasionally, there is a miracle.… I see these kids who are completely unscarred at 25 weeks as miracles and unfortunately they are not good news, because what they do is they give a lot, they give 90 percent of people false hope.… I don't know if I will ever be good or better on providing these couples with help as to what to do until we can overcome, manage, or improve the outcomes at 23, 24, and 25 weeks, which may never happen.

Only a few HCPs across disciplines discussed hope as a tool to help parents handle the stress of decisions, even if their infant later died or was born with impairment. These HCPs reported that the parents generally understood the information given to them and recognized that the parents felt a responsibility toward their child. As a result, these HCPs reported that, once given counseling, parents should be allowed to make the decisions. "I really don't find them living under a false hope … they seem to know realistically where they're at and in that sense they're really not hard to work with because they know." Some HCPs also discussed how overwhelming it can be for parents to process large amounts of negative information and give up on the infant's future. "I mean sometimes it's good for them to hear some positive thoughts.… All the possibility of positive thoughts."

Being influenced by experiences—HCPs who were involved in the counseling often described a local setting of pain, grief, and distressing events that affected their beliefs about parents' ability to understand prognostic information, understand the gravity of choosing to ignore their advice, and adapt if their child was born with impairments:

> Are we nuts and look at all this pain and suffering … how things have been lately, really affects how you feel right then and when you talk to parents … just how can you be optimistic when you feel like oh my God I just transferred to PICU for [a] trach[eostomy] … this [infant] had been in our unit for 110 days.… It really changes day to day, you know month to month, depending on how your own personal experiences had been.

A small number of HCPs discussed their perceptions of interdisciplinary (nursing versus medicine) and intradisciplinary viewpoints (within various specialties of medicine) related to hope. Some HCPs discussed how they at times found these differing viewpoints confounded effective communications between HCPs. They also pointed out that it was difficult to prevent such divergent viewpoints from being conveyed to the parents in subsequent communications. They believed these differing viewpoints likely added an additional layer of uncertainty and confusion for parents.

Finding a balance between hope and false hope—HCPs involved in the counseling and decisions discussed their struggle (moral distress) to balance the tone of the counseling sessions. Many described a dichotomy of hope (warranted hope) versus false hope (unwarranted hope) because of the outcomes they believed to be likely:

> [I] kind of temper hope with reality. And just be there and be willing to listen and answer questions and, you know, and give them the time that they need, because it, it takes a while. I don't think that the parents ever truly ever grasp what kind of road they're in for once these threshold viability babies are born.
>
> Usually when I see tears in her eyes; that is when they understand. They are in denial when they are smiling and happy, their baby is going to be perfectly fine and nothing I can do is going to convince them otherwise. [This particular mother] she had that clear acceptance; she understood the situation, while not a great one. I said, "But on the other hand, we were going to be there." I didn't want to take hope away. I said, "It is important to have hope that they will be at the better end of the possible range."

Staff nurses had a different role related to the sharing of information with parents. Rather than counseling parents, they reported that they were typically involved in re-explaining information and supporting the parents' needs (Kavanaugh, Moro, Savage, Reyes, & Wydra, 2009). Parents often reported that staff nurses were likely to share stories of infant survival and positive outcomes for families compared with those who gave them counseling. This helped to explain why staff nurses might be more likely to offer optimism to parents. Staff nurses often discussed the ways they shifted their prenatal interventional focus from always talking about the infant's life-support decisions to find various ways to support the mother:

> I mostly offered emotional support and you know validated the fact that she felt overwhelmed … was scared and unsure … about how it was a difficult situation and you know she had every right to feel the way that she was feeling.… We didn't always talk about the baby's life-support decisions, but I feel like these moms who are stuck in bed for weeks on end, even if they weren't having a difficult decision with their baby, they would be going crazy not having anyone to talk to, so it was mostly just building a relationship and validating the way she was feeling.

Discussion

A number of key points can be taken away from this investigation. Parents wanted a thorough and honest account of the available treatment options and (positive and negative) potential outcomes. Parents expected humility from HCPs regarding the uncertainty that exists when predicting prognosis in this population. Parents also desired HCPs to acknowledge that having a child with impairments might carry different meanings for parents than it does for HCPs. Parents stated that they were aware of the potential poor health outcomes for which their infant was at risk, but that they used hope as a way to endure the various prenatal treatments, overcome the fear of the unknown, and prepare for their family's future.

Most HCPs discussed the notion of hope as out of touch with reality and often described giving parents hope as misleading the parents from the truth, which they believed was ethically wrong. Only a few HCPs discussed the role of hope from the parents' perspective (emotional coping with uncertainty and as a cognitive motivator). HCPs involved in counseling often discussed the daily context in which they practiced and how this context can influence their beliefs and actions related to hope. HCPs who counseled parents often reported believing that they were most often non-directional in their counseling or interactions with parents, but parents often reported that they perceived otherwise. Taken together, parents' and HCPs' narratives give preliminary clues to how culture-based beliefs about hope influence communications related to periviable deliveries. These preliminary results need to be evaluated in future prospective studies.

Culture and Communication

Sapir (1949) recognized that people can come to communicative interactions with distinct cultural attitudes, beliefs, and expectations, and that these culture-based factors can affect what they talk about, the way they structure their talk to position their point of view, and how they interpret another person's talk. Similar to other literature and reports, parents in this study used hope to cognitively and emotionally face any potential change or loss, and to find positive meaning in what they reported others saw as grim situations (Boss et al., 2008; Charchuk & Simpson, 2005; Mack et al., 2007; Reder & Serwint, 2009; Scioli, 2007). Parents discussed that they were made aware of and understood the potential for poor outcomes if their child was born prior to 25 weeks, but often discussed a strong bond to their child and the difficulty of giving up hope as a parent when there is even a small probability that the child's future should be protected (Kavanaugh, 1997; Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005). In a study evaluating parents' perspectives, Reder and Serwint also found that parents reported that they needed to be the bearers of hope for their child, despite recognizing the grim health condition their child potentially faced.

We were able to inductively derive that the parents' arguments for inclusion of hope in periviable communications were rooted in the ethical principle of autonomy for decision-making (i.e., what was best for their family) and in an ethic of caring for their child. This ethic of caring stresses a need to care for persons, not simply because of the possibility of good outcome, but because of our interconnectedness with each other and a moral belief that it is the right thing to do (Gilligan, 1982). HCPs, however, often linked whether or not to maintain hope with whether or not there was evidence for a good health-related outcome for the infant. Because many HCPs believed that good health-related outcomes were not likely in a delivery prior to 25 weeks, they discussed moral difficulty in sharing any notions of hope with parents in this population.

It was more difficult to inductively derive a single ethical viewpoint from HCPs narratives. Their narratives often discussed the moral distress they experienced in telling parents what they believed to be the truth, which was poor prognosis and poor quality of life for the child and family, while also being supportive to parents. Previous investigators have found that clinicians often have feelings of guilt when surviving infants have impairments (Meadow & Lantos, 2009). Epstein and Hamric (2009) posited a crescendo effect, an increasing lower threshold of guilt, when moral distress is unresolved in situations that clinicians previously perceived as distressing. Persisting moral distress and guilt might in part explain some HCPs anchoring their information to stressing the potential for a negative outcome of the infant by some HCPs.

Anchoring hope to outcome of the infant alone and not the parents' or family's outcome seemed to frame how HCPs tailored their discussions with parents, determining what was important to discuss with parents, and how they viewed their moral obligation (i.e., truth-telling about the potential negative probabilities and minimizing or leaving out the positive possibilities because this would lead to false hope). HCPs described discipline, setting, and situational factors (culture-based factors), which influenced their beliefs about hope and their comfort level in expressing optimism to parents. These HCPs described intentions which revealed that they believed their communications and actions were caring (i.e., to help prepare the parents for what would lie ahead if they were to decide to maintain the pregnancy or revive their infant after birth); however, parents very often did not perceive these communications or actions as caring. The parents often described such actions as intentionally attempting to sway their decision ("bullying" or "pushing"). A plausible explanation for these divergent interpretations of the same communicative interactions would be divergent attitudes, beliefs, notions, and culture-based expectations about hope and the role that hope plays in this context (Philipsen, 1992, 1997, 2000; Philipsen, Coutu, Fitch, & Sanders, 2005).

Cultures or belief systems (e.g., HCPs as one culture and parents as another culture) typically devote a system of symbols, meanings, premises, and rules pertaining to communicative conduct, known as speech codes, and these speech codes likely influence how HCPs anchor information they give to parents at risk for delivering an extremely premature infant. A differing set of speech codes likely influences how parents interpret the same communicative acts (Philipsen, 1997). Speech codes related to hope played out in "the naming, interpreting, explaining, evaluating, and justifying of communicative acts" by the parents and HCPs involved in this investigation (Philipsen, 1997, p143–144).

Anchoring Communication

When dealing with such life-altering decisions, skilled communication is required to frame all the necessary information to be given to parents (Back, Arnold, & Quill, 2003; Thorne, Oglov, Armstrong, & Hislop, 2007). Several ethical issues complicate how the information is framed and what it might mean to those involved (Campbell & Fleischman, 2001). Parents in this study could not cite scientific data to support their reactions or arguments, but they often raised concerns in response to the perceived negative tone of information provided to them about their child's future. For instance, one parent raised the issue of the precision of the gestational age calculation of her infant and what it would mean if it was off even slightly. Many parents raised concerns about the accuracy of outcome predictions when so many different factors are involved in determining outcomes. Most parents noted that the meaning of raising a child with a disability might differ between parents and providers. Parents argued that the family's values and goals were of primary importance to the decision. Finally, all parents posited the importance of providing a full range of information, and not just the negative aspects. They insisted that discussions should address uncertainty, which they believed was inherent in predictions of outcome.

When HCPs anchor the notion of hope to the child's outcome alone (i.e., potential for death or impairment) then parents might perceive that the child is seen as a medical condition and not valued as a human being (Harnett, Tierney, & Guerin, 2009). Parents in this study often perceived HCP biases in the counseling or subsequent interactions. They discussed worrying that such bias might also influence the advice and options that HCPs discussed. Acknowledging uncertainty is one important way to balance out any anchoring of information when presenting diagnostic, treatment, and prognostic information (Back et al., 2003; Henry, 2006). Forman and Ladd (1989) have cautioned, however, that HCP training often conveys that professionals should communicate expertise to parents because of a belief that this gains parents' trust.

Acknowledging uncertainty is also important to truth-telling, because although gestational age is strongly associated with impairment, each infant's outcome cannot be specifically and precisely predicted (Chiswick, 2008; Tyson, Parikh, Langer, Green, & Higgins, 2008). In addition, HCPs might believe that raising an extremely premature child can only bring sorrow and strife to the parents. Evidence suggests, however, that this is not how many parents feel about their experiences (Saigal, Pinelli, Streiner, Boyle, & Stoskopf, 2010; Yuan, 2003).

Discussions that include the various additional cultural factors that can influence parents' decision-making and ultimate meaning (i.e., previous experience, spiritual beliefs, or other values or resources they have identified) are justified in these conversations as a way to balance the medical information provided to parents. Additionally, by anchoring hope on the shared goal of helping the parents to transition through this difficult time and make the decisions that fit with their values and goals, the HCP demonstrates his or her shared interest in working toward what is good for each family (Feudtner, 2007; Swanson, 1993).

Swanson (1993) pointed out that positive optimism or hope is an essential component of caring, calling it *maintaining belief*. She defined this form of optimism as "a fundamental belief in persons and their capacity to make it through events and transitions and face a future with meaning" (p. 354). When supported in their informational needs (i.e., given the full range of information, given time to discuss and ask questions, and supported in their final decision) we assist parents to make decisions that they can live with. Although parent may initially grieve the loss of the child they expected, when receiving a bad prognosis, parents can transition to find positive meaning in their final choice, even if the child later dies or is born with impairments of any kind.

At times, HCPs may have limited time to learn about parents' values and goals and develop a trusting and caring relationship when there is a seemingly imminent delivery and potential threats to the mother's or child's immediate health condition. The need for quick decisions to be made and the uncertainty inherent in such a quickly formed relationship can complicate communication even more (Berger, 1997). Yet, making every attempt to still clarify parent and family values, goals, and desires, and incorporating these into the subsequent discussions is important. This process helps the parents to see that the problem (i.e., their need to make a difficult decision that is right for him or her) is recognized by the HCPs and being worked on by all involved parties (Mack & Wolfe, 2006). When parents perceive that they are not allowed to express their beliefs, goals, and needs, or when they perceive that their position is not valued by the HCPs they are working with, they can feel disconfirmed and disadvantaged. Such interactions can potentially result in failed immediate and future communications and emotional angst that can last well beyond that initial interaction (Feudtner, 2007; Philipsen, 1992).

Considering Identities, Time, and Place of Communications

Philipsen (1997; 2005) has pointed out that when two or more people connect through a spoken interaction, that interaction is located within a particular time and place, and their subsequent discussion about that communication reveals each individual's perception of socio-environmental conditions shaping that interaction. These include: (a) the setting of the communication; (b) the participants' identities and their perceived resources; (c) what he or she perceives is meant by each other's talk; (d) what he or she perceives the other is trying to do with their words; (e) the expectations he or she has regarding how the other should have communicated; and (f) the type of talk. Thus, by evaluating the way each person and group talked about the role of hope in related to their prenatal communications, we were able to gain a preliminary understanding of how culture-based beliefs about hope potentially structure these conversations and result in the positive and negative reactions that parents conveyed in their talk. Parents in this study placed an emphasis on the perceived: (a) communicative conduct of HCPs; (b) power differences inherent in this environment; and, (c) whether there was anchoring of information or an attempt to present the full range of information (Boss et al., 2008; Mack et al., 2007; Miquel-Verges et al., 2009; Reder & Serwint, 2009; Wocial, 2000).

Parents' narratives illustrated that they enter into these communicative interactions with expectations of a trusting, caring, and collaborative relationship with their HCPs (Berger, 1997; Philipsen, 1992). These expectations likely affect how parents interpret their interactions with HCPs, especially when uncertainty and bad news is involved (Berger, 1997; Feudtner, 2007; Philipsen, 1992, 1997). Parents might focus on certain aspects of the communication conduct, such as the information shared or omitted, tone or specific words chosen to describe the infant, the incorporation of other information into the decision-making process (spirituality or the parent's previous experiences), body language that is also symbolic of meaning, and the time spent explaining and discussing these decisions. These things can influence how parents interpret the entire speaking interaction and might result in them perceiving the interaction quite differently from its intended meaning (Feudtner, 2007; Philipsen, 1992, 1997, 2000; Philipsen et al., 2005; Philipsen, Leighter, & Cooren, 2007).

Clinicians might intend that their behaviors in a particular communication are caring and nondirective, yet their focusing on particular aspects (anchoring) might ultimately affect the perceived positive or negative focus of their subsequent talk (Feudtner, 2007; Harnett et al., 2009). Feudtner suggests that one way to prevent anchoring is to recognize anchoring in the conversation, draw attention to it, and then purposely discuss the alternative position. This suggestion is in line with how parents described the need to receive all information (positive and negative), so they are informed and prepared; however, they pointed out that it was also important to discuss the uncertainty present in the prediction of outcomes for this population.

To engage in collaborative communication surrounding emotionally charged issues, such as outcomes related to periviable delivery, providers must acquire emotional intelligence. Emotional intelligence is the ability to competently process information that is laden with emotion, guide problem-solving, and focus one's subsequent energy on the necessary behaviors to improve interactions and communications (Feudtner, 2007). Emotional intelligence requires the HCP to: (a) accurately perceive the other's emotions and aptly express their own emotions; (b) be able to interpret and reflect on their own emotions correctly (i.e., I am frustrated with my own inability to do something to help this family as opposed to I am frustrated with these parents); (c) use their emotions to reflect and subsequently improve their thinking or communications; and, (d) manage their own emotions so that they can positively influence the parents' emotions when communicating collaboratively. Otherwise, in some contexts, certain HCP communicative strategies might reduce some aspects of uncertainty (i.e., what it will be like) while escalating other aspects of uncertainty at the same time (i.e., the parent's perception that they can make the decision and they will be supported in their decision) (Penrod, 2001).

According to the parents who reported positive interactions, HCPs facilitated parents' ability to have and maintain hope by providing them with a full range of information about prognosis and treatment options, allowing them reasonable space and time to make their decisions, supporting their final decisions, and demonstrating a shared goal for a positive future (i.e., "I hope this treatment helps" or "I hope for the best."). Such statements acknowledge the HCP's own caring emotions, demonstrate that they are empathetic to the parent's emotional state, and validate that the HCP and parent(s) are working together for the best possible family outcome (Feudtner, 2007).

Parents placed a great deal of importance on knowing that all reasonable treatment options were being used for the mother or infant to improve the likelihood of a positive family outcome. Many parents' prenatal narratives also highlighted their lack of knowledge related to fetal development. Clinicians might need to thoroughly explain early stages of infant development, in terms parents can understand, and how the stages of development affect which therapeutic options are available at various points in development. This information can be confusing to parents, especially given their emotional state, and even if explained to parents, it might need to be explained several times (Feudtner, 2007).

The angst expressed in many parents' narratives, via their tone of speaking, words used, and the rhetorical nature of their reactions suggested that they frequently had perceptions of being disadvantaged in the hospital setting, related to many of the communications they experienced related to decision-making. They discussed issues relating to the language used, the positioning of probabilities above other information parents also believed to be important (their values and goals), being approached by multiple HCPs, and a lack of consideration for the parent's or family's questions or input. Many of the narratives suggested that it is important that parents believe that HCPs offer information that is therapeutically based and not based on personal or medical values related to infants born with impairments or with a potential to die (Janvier et al., 2008; Janvier, Leblanc, & Barrington, 2008).

Parents in this study most often expressed wanting to actively participate in decision-making for their infant and family (Harrison, Kushner, Benzies, Rempel, & Kimak, 2003; McHaffie, Laing, Parker, & McMillan, 2001; Zupancic et al., 2002). Others have pointed out that even when parents prefer not to make the decisions, they generally want to be included in any discussions, receive updated information, have their concerns understood and acknowledged by providers, and have others acknowledge that any final decision ultimately affects their family (Brinchmann, Førde, & Nortvedt, 2002).

Limitations

Caution should be applied when generalizing from these findings to other parents or providers. The original study was conducted in a distinct region of the United States and only captured an English speaking sample from three local hospitals in an urban city. The original study also only captured the parents who opted for hospitalization and whose health condition did not prevent them from being interviewed prior to delivery. The HCPs included in this study were only those referred by the parents as having been involved in information delivery or information clarification. The group of parents and providers not included in this study might represent different viewpoints. Although saturation of themes seemed to be present in parents' narratives, it was difficult to tell if we reached saturation in the themes for HCPs because of the variability in representation of disciplines and sub-disciplines for the sample. The time that passed between conducting the interviews and analyzing these findings resulted in a loss of contact with most of the parents, which prevented us from acquiring member feedback on these findings.

Clarifying the divergent conceptualizations of hope between HCPs and parents was not initially included as one of the primary aims of the original investigation. Thus, an in-depth exploration of this concept with parents and HCPs was beyond the scope of the original investigation. The divergent ways in which HCPs and parents discussed the concept of hope, and parents' descriptions of the potential emotional and behavioral implications warranted this analysis. Culture-based beliefs about hope should be explored in depth with these two groups in future studies. This area of study is critical because culture-based beliefs can have a profound effect on shaping communications and subsequent provider and parent relationships.

There were obvious age, racial, ethnic, religious, education, and discipline differences among those interviewed, and these cultural differences might also influence participants' responses. Parents, however, did not discuss these factors as directly salient to their appraisals of interactions with HCPs. Instead, parents reported that it was whether or not they believed HCPs held negative views on having an infant born with impairment and whether or not HCPs believed that parents were capable of making a competent decision. The differing socio-demographic factors (i.e., education, race/ethnicity, economic, religious) might indirectly affect communications in this context. Previous research has shown that socio-demographic differences between HCPs and patients/family members can contribute to health disparities via differences in the very nature and content of communications (Ackerson & Viswanath, 2009). A future prospective study focusing on the differing attitudes, beliefs, notions, and culture-based expectations of each group might be able to capture how differing socio-demographic factors play out in the actual delivery and appraisal of these communications.

Implications

This analysis offers provocative descriptions of how divergent culture-based beliefs about hope might be an antecedent to problems in communicative interactions, influence the characteristics of interactions between HCPs and parents, and influence parents' appraisals of supportive care versus being controlled. There are still many unanswered questions about communicating with parents who are risk of delivering prior to what medical science determines in viable.

Future research should prospectively focus on the various notions of hope among differing stakeholders and include the various disciplines within health care who interact with parents at risk of delivering an extremely premature infant. Recruitment in future studies should also occur from hospitals in varied locations because culture within a geographical setting or within a hospital system could also affect communication dynamics with parents. This approach could aid in capturing both the broader and specific socio-cultural influences on various individuals' notions of hope. A future study could also concentrate on capturing how parents' conception of hope might change over time. The addition of thicker qualitative description would lead to a more nuanced understanding of how various notions of hope influence counseling communications and later interactions with parents at risk of delivering extremely premature infants.

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