

The Decision to Continue: The Experiences and Needs of Parents Who Receive a Prenatal Diagnosis of Holoprosencephaly

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Holoprosencephaly (HPE) is a condition characterized by a defect in the development of the midline embryonic forebrain. When detected prenatally, the diagnosis of HPE offers parents a poor but often uncertain prognosis. Since the majority of parents receiving a prenatal diagnosis of an abnormality terminate their pregnancies, few studies have examined parents' experiences and needs surrounding the decision to continue a pregnancy. We present a descriptive study of in-depth interviews with 24 parents who chose to continue their pregnancy after receiving a prenatal diagnosis of HPE. Parents were asked about their decision-making process to continue the pregnancy. Qualitative analysis was used to identify common themes that emerged from these parents' experiences. The results suggest that most parents did not make an active decision about continuing the pregnancy. Rather, they described a more subtle decision-making process that evolved over time and consisted of several factors. These factors included the parents' religious and personal beliefs, past experiences, and the uncertainty involved in the diagnosis of HPE. Throughout the decision-making process, they described informational, emo-

tional, and supportive needs from family, friends, and health professionals. All of these factors contributed to the evolution of the parents' decision to continue the pregnancy and the acceptance of their decision. Results of this exploratory study suggest health care professionals need to work with parents as they make their decision to continue an affected pregnancy. The results also provide the groundwork for prospective investigation into parents' decision-making process as they receive and adjust to prenatal diagnoses of an abnormality.

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INTRODUCTION

Holoprosencephaly (HPE) is a condition characterized by a defect in the midline of the embryonic forebrain. It affects 1 in 5,000–10,000 live births worldwide [Ming and Muenke, 1998; Muenke and Beachy, 2000]. HPE manifests in varying degrees in the brain, face, and other midline structures and may include craniofacial anomalies ranging from cyclopia to cleft lip and palate, single central incisor, mental retardation and developmental delay, seizures, hydrocephalus, feeding problems, unstable homeostatic mechanisms, and neuroendocrine abnormalities.

When HPE is detected prenatally, parents are given a poor but often uncertain prognosis for their baby. Similarly, parents of children born with HPE are often told their children will die within days or weeks of birth. Depending on the range of severity, however, the prognosis for individuals is quite variable. Severely affected neonates may only live for several days or months, and

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mildly affected children may live a normal life span [Barr and Cohen, 1999].

Prenatal diagnosis of a fetal anomaly is devastating for parents and can be viewed as a time of crisis, producing grief that invokes stages of shock and disbelief, denial, anger, and eventually adaptation and adjustment [Quine and Pahl, 1986]. Parents often experience a time of "chronic sorrow" and have reactions similar to those grieving perinatal loss [Pueschel and Murphy, 1976; Svarstad and Lipton, 1977; Matthews, 1990]. Prenatal diagnosis of an abnormality is particularly devastating in the case of an inadvertent diagnosis by ultrasound [Sandelowski and Jones, 1996]. Because the possibility of detecting a fetal abnormality is not often the reason for performing an ultrasound, couples may be unprepared for the news of an abnormality [Green, 1990]. Health care providers can help couples who receive a prenatal diagnosis of an abnormality by giving clear, honest, and understandable information, providing a supportive and caring environment, and allowing adequate time for discussion [D'Arcy, 1968; Chescheir and Cefalo, 1992; Chitty et al., 1996; Biesecker, 2001].

The decision-making process following prenatal diagnosis of an abnormality is complex. Many factors have been identified that influence the parents' decision to continue or terminate the pregnancy. These include the parents' experience with an affected child [Beesen and Golbus, 1985], gestational age at diagnosis [Verp et al., 1988], religious beliefs [Meryash and Abuelo, 1988], knowledge of genetics [Metheny et al., 1988], and the seriousness of the condition [Hassed et al., 1993; Pryde et al., 1993].

Studies of parents who continue a pregnancy mainly focus on the effect of the results on the remainder of the pregnancy. Several studies have shown that after receiving a diagnosis of an abnormality, women were emotionally unbalanced for the rest of the pregnancy and had strong emotional reactions, such as eating and sleeping disorders, anger, and sadness [Jorgensen et al., 1985; Hunfeld et al., 1993]. Often the likelihood of survival or the child's prognosis cannot be predicted, so parents are faced with the task of adjusting to a largely uncertain future [D'Arcy, 1968; Horger and Pai, 1983].

Few studies have been done on the actual decision-making process following the diagnosis of a fetal abnormality [Marteau, 1995]. As a result, we do not know about parents' experiences and needs when they are making a decision to continue a pregnancy given a diagnosis of an abnormality. In addition, we do not understand how health care professionals can best serve the

needs of parents during the decision-making process and throughout the remainder of the pregnancy.

This study takes a first step toward filling in these gaps by using a qualitative methodology to explore parents' experiences and needs through the decision-making process to continue a pregnancy following a prenatal diagnosis of HPE. The goals of the study were to: 1) explore with parents their experiences in making the decision to continue the pregnancy; 2) identify informational, emotional, and supportive needs of parents throughout their decision-making process; and 3) gain insight from parents about better/different strategies that health professionals could provide for individuals facing similar diagnoses and decisions regarding continuation of a pregnancy given the prenatal diagnosis of an abnormality.

METHODS

Study Population and Recruitment

A total of 24 parents participated in the study (10 couples and 4 mothers). They were recruited through a variety of sources, including: 1) The National Institutes of Health Conference on HPE, a scientific, clinical, and family conference sponsored by the National Human Genome Research Institute (NHGRI) on April 16, 2000; 2) the Carter Centers for Brain Research in HPE; 3) the University of Michigan; and 4) support resources set up for families affected by HPE, including a newsletter, website, and chat room. Letters along with response postcards were mailed to parents registered to attend the conference or registered with the Carter Centers. Parents at the University of Michigan were contacted by telephone by a staff member not affiliated with the study and given contact information. Recruitment ads with contact information were placed in the HPE support resources. Table I describes the response rate of parents recruited through each site.

Inclusion criteria were that parents 1) received their child's diagnosis of HPE prenatally, 2) continued the pregnancy, and 3) were over the age of 18 at the time of participation.

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Data Collection

Interested parents were contacted by telephone to explain the study, assess eligibility, and answer addi-

TABLE I. Recruitment

Sites	Letters mailed	Responded	Declined	Total
HPE conference	15 couples	4 couples	—	4 couples
Carter centers	11 couples	6 couples	1 couple 3 fathers	2 couples 3 mothers
University of Michigan	—	1 couple	1 father	1 mother
HPE resources	—	9 couples	5 couples	4 couples
Total	26 couples	20 couples	6 couples 4 fathers	10 couples 4 mothers

tional questions. If the parents agreed to participate, an interview time was arranged. In-person interviews were conducted for 8 parents attending the conference, and telephone interviews were conducted for 16 parents recruited through the remaining sites. Written consent was obtained from all participants. In families in which both parents agreed to participate, the interviews were done separately and in immediate succession to prevent cross talk about the interviews.

All interviews were conducted by K.R.G. and were audiotaped. The interview included open-ended questions about the parents' experience of receiving the diagnosis, his/her needs from the time of the diagnosis until birth, and the perceived informational, emotional, and supportive roles of involved health care professionals. A brief demographic questionnaire was administered following the interview.

Data Analysis

The audiotaped interviews were transcribed verbatim. The data from the qualitative interviews were analyzed using thematic analysis, an inductive approach to the data that involves looking for patterns, themes, and common categories [Silverman, 1993].

This study focused on the parents' decision making to continue the pregnancy. This theme was chosen given the frequency and depth in which it was discussed within the interviews. Specifically, this theme could be grouped into two different categories that emerged from the data: parents' experiences while making the decision, and their needs from family, friends, and health care professionals.

Coding was performed by K.R.G., and a second coder (B.B.B.) coded 40% of the data to qualitatively assess the reliability of the coding process. All data were analyzed collectively with no within- or between-couple comparisons. Given that the purpose of the study was not to compare parents' experiences, reported results represent experiences of individual parents rather than couples.

RESULTS

Sample Characteristics

A total of 24 parents, 10 couples and 4 mothers, participated in the study. Table II describes the socio-demographics of the parents, and Table III describes the characteristics of the children with HPE as reported by the parents. Overall, participants were white, non-Hispanic, with middle-class incomes and had completed a high school education.

The Decision-Making Process

Parents, in discussing their experience of receiving a prenatal diagnosis of HPE, frequently focused on their decision to continue the pregnancy. For some parents this decision was made at a particular time in pregnancy, when they faced a choice to terminate or continue the pregnancy ($n = 9$). For others, the diagnosis was received late in pregnancy and the option to terminate had passed ($n = 5$). Regardless of the time of diagnosis,

TABLE II. Characteristics of Research Sample

Characteristics of parents ($n = 24$)	
Gender	
Male	10
Female	14
Average age	33.8 years
	Range: 23–50 years
	SD: 7 years
Race	
White, non-Hispanic	21
Hispanic	2
Asian/Pacific Islander	1
Current marital status	
Single, never married	1
Married	22
Separated or divorced	1
Number of living children	
None	1
One	14
Two	5
Three	4
Current household income	
Less than \$20,000	3
\$20,000–\$35,000	3
\$35,001–\$50,000	7
\$50,001–\$75,000	9
Greater than \$75,001	2
Religious background	
Catholic	13
Protestant	7
Baptist	4
Highest education level completed	
Any high school	12
Any college	6
Any graduate	5
Any post-graduate	1
Current employment status	
Full-time	15
Part-time	2
Not employed	7
Health insurance	
Yes	23
No	1

each parent described the decision to continue the pregnancy as an evolving decision that they revisited throughout the pregnancy. Parents, in answering the open-ended questions, would freely return to discussions about the process of reconsidering their decision to continue their pregnancy. Themes regarding this decision as a process, as presented in the following results, were present throughout the interviews.

Parents' Experiences

Making the decision. The parents' decision to continue their pregnancy was influenced by multiple factors. Some parents talked about their decision in terms of their religious beliefs. Parents often said their religion prescribed their decision, making statements such as "we're Catholic, and you're not supposed to have an abortion" or "we didn't want to have an abortion basically because it had a lot to do with our religious faith."

Parents' belief in God also influenced their value of life and acceptance of their decision. Many parents said that

TABLE III. Characteristics of Children Diagnosed With HPE

Characteristics of affected children (n = 14)			
Gender			
Male		8	
Female		6	
Status of living child			
Living		8	
Average Age		3 years, 4 months	
Status of deceased child			
Deceased		6	
Average age at death		2 years, 8 months	
Mode of diagnosis			
Ultrasound		14	
Average time of diagnosis			
		22 weeks	
		Range: 12–40 weeks	
		SD: 6.7 weeks	
Average time from diagnosis to interview			
		3 years, 6 months	
		Range: 6 months–12 years, 5 months	
		SD: 2 years, 11 months	
Type of holoprosencephaly			
Alobar		6	
Semilobar		4	
Lobar		3	
Unknown		1	
Physical traits			
Cleft lip	6	Delayed speech	9
Cleft palate	6	Moderate learning difficulties	3
Cyclopia	2	Severe learning difficulties	10
Mood swings	1	Problems with sleep patterns	7
Seizures	8	Difficulty controlling movements of head, arm and legs	8
Growth delay	5	Unstable heart rate	6
Feeding problems	10	Unstable temperature	7
Digestive problems	7	Delayed understanding of words	7
Deaf	2	Diabetes insipidus	3
Blind	2	Underdeveloped genitalia	1
Diaphragmatic hernia	1	Orthopedic problems	1
Hypothyroid	1	Hypopituitarism	2

they felt that it was “God’s plan” and that the diagnosis and decision “happened for a reason.” As one mother said, “When you leave everything in God’s hands then you rest. . . . It is not in your hands.” (Mother 3)

Many parents, unrelated to religion, based their decision not to terminate the pregnancy on a personal belief system. Some felt that it was “selfish to think that way” and that “it just didn’t seem right” for them to make a decision to terminate the pregnancy. For many, their personal belief system involved a “value for life” and the belief that you “accept what you have been given.” Many parents stated that part of acceptance of their decision involved valuing their decision to have children:

Basically, we decided together that you don’t determine your baby’s worth by what they look like, or what they have, or don’t have. You decide to have children, then you decide to have children. (Mother 7)

For some parents this personal value allowed the decision and fate of the pregnancy to be ascribed to the child.

Many parents discussed the perceived uncertainty involved in the diagnosis of HPE as a factor in their decision to continue the pregnancy. This perceived uncertainty was often the result of the lack of available information on HPE for parents, which forced them to base their decision on ambiguous and often unclear information. As one parent stated, “It’s scary to think that so much of it [the decision] is based on information you get, because they don’t know.” (Mother 6) In addition, many parents received different prognoses and explanations of HPE with each ultrasound or clinical visit. This magnified the perceived uncertainty involved in HPE.

Parents’ feelings toward pregnancy termination also influenced their decision. For two fathers, these feelings originated from past experiences with pregnancy termination. For other parents, feelings of anticipated guilt, especially coupled with the hope of having a normal baby, influenced their choice to continue the pregnancy:

That was my own selfish reason not to do it, just the guilt on me. . . . I don’t think I can live with myself if we said we can’t handle this anymore,

let's induce, and then she's healthy and she dies because it's too early. (Father 4)

Parents talked about their previous personal experiences as influencing their decision to continue their pregnancy. One mother talked about having a brother with HPE. Two other couples talked about their history of infertility. For these couples, the fact that they had "tried so hard" to have children made it difficult to imagine ending the pregnancy.

Coping with the decision. For the remainder of the pregnancy, parents described experiencing an ongoing process of coping with their decision to continue the pregnancy. Throughout this process, parents described various coping strategies (Table IV). At different stages following the diagnosis, parents described using different coping strategies that were sometimes in reaction to others' responses to their decision. Some parents described these strategies as familiar and comforting ways for them to cope with their decision. For others, these strategies were foreign and left them with feelings of doubt and confusion.

Parents' Needs

Informational needs. Almost all parents said they needed more information about HPE. Parents often said that this information would have been helpful in making their decision:

If they had provided us with better information ... to direct us to a specialist ... actually help us deal with what we're facing. (Mother 8)

The information parents did receive from health care professionals was described as containing "little to no hope" or as the "worst" thing that could happen. One parent stated, "The healthcare providers need to just temper their scientific diagnosis with caution. Know that you can't talk about everything in black and white." (Father 5)

In addition to wanting more hopeful information, parents also said it would have been nice for the health care professionals to acknowledge the uncertainty involved in HPE. Many parents felt they didn't always need answers, but wanted providers to admit that they did not know a lot about HPE or their baby's prognosis. One mother stated:

Finally, I told my husband, I said, "You know I just wish one doctor would come and go, 'We don't know what to tell you. We don't understand this.'" (Mother 8)

Many parents searched the library and the World Wide Web on their own for more information, especially information that could offer them the hope they were seeking. However, once parents found information, they discovered that HPE was described with the same "doom and gloom" prognosis.

Emotional needs. Many parents stated that in addition to referrals to other HPE families, it would have

been helpful to get in touch with organizations that supported their decision to continue the pregnancy:

He could have said, "Well listen, this is somebody you can get in contact with." Depending on which avenue you took, get in touch with one of the organizations that promote that... We could have found out about First Steps prior to that and had a little bit of help with figuring out about visiting the funeral home. (Father 3)

Many parents stated that it would have been useful to be put in contact with people or organizations offering information about HPE. Parents stated that those facing a decision about a pregnancy with HPE should talk to other parents to know that there are children that are "alive and living" with HPE. One parent described finding the Team 17 chat room for parents with children with HPE and finding out "they did have living children with it, so we had never even thought of terminating the pregnancy because we were given hope and comfort through them." (Mother 5)

Supportive needs

Family and friends. Many parents described feeling unsupported by family and friends during their decision. Some family members challenged their decision to continue the pregnancy. One parent said, "My grandmother had mentioned that she wished she could override our decision and talk to the doctors, because a lot of my family couldn't understand why we were putting ourselves through this." (Mother 5) For many parents, it was their parents, the child's grandparents, that openly disagreed with their decision to continue and expressed concern for the parents' ability to handle the emotional responsibilities that accompanied their decision.

Parents indicated that reactions like these made them feel they were letting others down, particularly expectant grandparents. Some parents felt that their friends didn't understand why they would "want a baby like that" and were concerned about the "burden" they were taking on for themselves and their other children. Many parents stated that these comments made them feel isolated and unable to share their feelings with family and friends. Parents then turned to their spouses for support.

In contrast, some parents described very supportive actions and words from others. They found it helpful when family and friends were not "just feeling sorry for us," but were strong for them, accepted their decision and the baby "no matter what," and "just helped me deal with it in the way I needed."

Health care professionals

Not helpful experiences. Many parents described incidents when they felt health care professionals' words or actions were not supportive, especially after just receiving the diagnosis of HPE. Many parents felt professionals sent them messages to terminate the pregnancy, that it "may be best" or that it was "what most parents would choose." One father, who described being advised directly by health care providers to terminate the pregnancy, said:

TABLE IV. Parents' Experiences: Coping With the Decision

Coping strategy	Description	Parents' words
Spirituality	Faith and spirituality gave parents help, comfort, and support. Supportive relationships with pastors, priests, and church members gave parents strength and reassurance that they had made the right decision	"I think my faith really kept me going. And I think if I hadn't had God in my life. I have no idea what I would have done. My pastor, he said, 'You don't know what's going to happen. If it does happen that's what's supposed to happen, there's a reason, you may never know.'" (Mother 8)
Maintaining hope	Hope allowed parents to "live" with their decision in different ways: Hope that the diagnosis was incorrect	"But finally, we just made the decision that we wouldn't change anything because they could be wrong, we could hope, she could come out normal, you know, who knows, because you hear of these things . . . And she's moving around and kicking, and you're thinking, now how can there be something wrong with this baby?" (Mother 5)
	Optimism	"I have a tendency—as long as it doesn't look like we're circling the bowl about to go down—I'm going to stay hopeful (Father 10)"
	Wishing for a miracle	"I was still praying every time I went for an ultrasound for a miracle. That it was going to be a mistake." (Mother 10)
Normalizing the pregnancy	Normalization was a strategy parents used to "return to their pregnancy" and attempt to enjoy the remainder of the pregnancy	"I had always made the kids a blanket, a quilt, so I made her one. And I thought, well, she could be buried with it, or have it. So I thought, I'm not going to do any different for her than I would for the others as far as not having something for her when she was born. So that was good." (Mother 4)
Denial	Denial and deflecting the diagnosis was a strategy parents used to "not dwell on it" and "turn this (the diagnosis) around"	"He (the baby) was very active . . . And I just kept saying, you know, they're going to be wrong, he's going to be born just fine. That was my way of getting through it." (Mother 11)
Expecting the worst	Parents prepared for the worst outcome in order to allow themselves to not be let down or be "pleasantly proved wrong"	"So, you know we were expecting the worst. You know, when you are expecting the worst, whatever happens, even if the diagnosis was still the same, you were expecting more things like death." (Mother 3)
Preparation	Planning the remainder of the pregnancy, both emotionally and physically, was a strategy parents used to prepare for all the uncertainties. Plans included: funerals, donations of organs, comfort care, arrangements for treatments, and possible surgeries Mental preparations were also done to plan for the future of their baby	"We tried to cover all of our bases with planning. There's different homes throughout the city here, and home care, and then planning a funeral as well, and dealing with all that, and picking out caskets . . . it just seemed so insane, but . . . we needed to do this to prepare." (Mother 5)
Death ambivalence	Parents described being torn between preparing for the possibility that their baby may die and secretly hoping that their baby may not make it	"You have all these thoughts that go through your head like, well, is she going to live, what's she going to look like, is she going to have to go into a home, will we be able to care for her . . . And then you think well, down the road, what if something were to happen to us, who would take care of her? And she's not even born yet, and you're thinking all those things (Mother 4)" "The emotions you get, because I mean, there's part of me that didn't want all this to go on, and just wanted life to go back to normal. And I remember reading one of the books that was like, some people even wish their child would die. As bad as that is, that's kind of how I was feeling." (Father 1)
Bargaining and social comparison	Parents set limits for what health and physical features they could and could not accept for their baby. Examples of these limits were raised by many parent when they talked about coping with the facial anomalies involved in HPE. Parents were concerned about social acceptance of their baby	"If she was born with her brain missing and she was going to pass away, that was one thing. But I felt kind of sorry for her . . . hopefully, she wouldn't realize that she had problems with her face . . . something made me feel like that's not right for her . . . not only is she not going to live, but she's going to have some abnormality of the face." (Father 4)
Acceptance	Parents described an eventual acceptance of their decision and the baby. Parents had worked through many emotions throughout the pregnancy and had begun to accept the uncertainty of the baby's future	"So we started to ask Him (God) why not us? When we changed the question from 'Why us' to 'Why not us' I think we changed our perspective on what to do. So, when he was born, we were prepared." (Mother 2)

Having your doctor that you've gone to for 10 years all of the sudden be like, this pregnancy isn't going right. Let's just start over. . . . You're like, oh, so now we're just done? That's the part I think that was the most puzzling part to me. (Father 9)

Parents, particularly mothers, often felt like health care professionals were more concerned for the mother's safety than the safety of their baby: "He said, 'I've got one patient I can do anything for and that's you, and the best thing we can do is get you unpregnant as quick as possible.'" (Father 1)

Some parents said that their health care provider was opposed to their decision to continue the pregnancy. Other parents felt like they were going against professional wishes, that they were crazy for continuing the pregnancy, or that they might get different care after deciding that they were continuing an "abnormal" pregnancy.

Some parents described feeling isolated from their providers because of their decision. One parent described the isolation as resulting from providers taking a neutral stand with regard to abortion:

It would have been nice if we felt a little more supported after we made the decision. But they just kind of stayed neutral, and didn't want to go one way or the other. Maybe they felt that they couldn't because of the position, because they couldn't support or not support because they are in that profession . . . but it would have been nice to have a little more encouragement. (Father 3)

For other parents, this isolation came from the change in the way they felt treated after making the decision to continue the pregnancy, that the professionals "stepped back." Other parents stated that they felt that this isolation was purposeful and was the result of liability concerns. One father said:

You got a very, what I frankly felt to be, a very liability conscious set of recommendations. . . . It was a whole lot of cover-your-ass type of responses. . . . The immediate recommendation was, "what we need to do is go ahead and you can have an abortion and we'll take care of it," which, to me, becomes a doctor practicing law rather than medicine. (Father 8)

Helpful experiences. For many parents, helpful experiences around their decision to continue the pregnancy involved receiving support and respect. Parents described fearing that they wouldn't be supported in their decision to continue, especially when they felt very encouraged to terminate the pregnancy. Thus, parents said that it was helpful and a relief to feel that "when they chose what they chose, he [the doctor] was still supportive." Parents were grateful for health care professionals who supported their feelings and never imposed their beliefs and judgments on them.

Other helpful experiences involved feeling good about the way that the health care professionals treated them

and their baby. One mother (Mother 7) said she liked to see only the ultrasonographers because they were "respectful" and "nurturing" of her and her baby even though the fetus had the diagnosis of HPE. When health care professionals treated their baby with respect, parents were grateful because they felt others believed their child "had meaning."

Following the delivery of their child with HPE, several parents described helpful experiences with health care professionals who were continuously supportive of them from prenatal diagnosis through caring for the health problems of their baby and sometimes the death of their child with HPE:

That's what I loved about Dr. Y. Because he would often say that "I'm not just here to take care of the baby, I'm here to take care of the whole family." (Mother 14)

Other parents said it was helpful to work with pediatricians who, even though they didn't know about HPE, were willing to learn about it through reading the literature.

DISCUSSION

In this study, 24 parents were interviewed about their experiences of receiving a prenatal diagnosis of HPE. In doing so, we provided parents with an opportunity to share, in their own words, the process that they underwent in deciding to continue their pregnancy. For most parents in this study, the decision to continue the pregnancy was not an active choice but more often a subtle, passive decision. As illustrated by the depth and breadth in which parents described this process, parents did not voice their decision to continue the pregnancy as a simple yes or no decision. Rather, they described an initial decision to continue the pregnancy, followed by a continued effort to cope with their decision for the remainder of the pregnancy. This decision evolved over time and was influenced by multiple factors: their beliefs, values, prior experiences, the uncertainty of an HPE diagnosis, ways they coped with the decision, and their informational, emotional, and supportive needs.

Many of the factors described in this process are not dissimilar to those previously described in the literature. The importance parents placed on their religious beliefs, personal values, and individual and cultural framework to help them through their decision-making process is consistent with previous studies on parents continuing pregnancies after the prenatal diagnosis of an abnormality [Palmer et al., 1993; Allen and Mulhauser, 1995]. These factors can also be interpreted as resources parents utilize to find order, purpose, and meaning in a stressful life event [Affleck et al., 1991]. Factors such as spirituality provided parents with a framework in which to make their decision. Relying on God's plan, drawing from past experiences, or belief in fate allowed parents to appraise their situation and helped them to shape their decision as one that they did not merely select alone.

The uncertainty involved in the diagnosis of HPE also factored into parents' passive decision-making process.

Other studies have shown that the seriousness of a condition, as defined by medical findings, is a consistent predictor of whether parents terminate or continue a pregnancy diagnosed with a prenatal anomaly [Drugan et al., 1990; Hassed et al., 1993; Pryde et al., 1993]. In this study, however, many parents' perceptions of the uncertainty in HPE significantly influenced their assessment of the seriousness of the diagnosis. On one hand, they were told that the prognosis in HPE is poor. On the other hand, parents did not receive a lot of information about HPE or found the interpretations of the medical findings in their baby changing with each doctor or specialist visit. As a result, parents' perceptions of uncertainty in the diagnosis of HPE ultimately superceded the medical seriousness of the prognosis they were given. Parents wanted health care professionals to acknowledge this uncertainty. We can only hypothesize about how the lack of concrete or absolute information influenced these parents' decision to continue their pregnancy. Perhaps this perception of uncertainty led parents to believe or hope for a milder course of illness, or rather, the uncertainty made the continuation of the pregnancy and adjustment to their decision more difficult. In either case, this suggests that health care professionals need to be aware of and listen to the parents' perceptions of a diagnosis. Individual perceptions of a diagnosis play a role in how parents assess and reassess their decision to continue a pregnancy.

A factor that has not been previously explored in the literature is the many ways in which parents cope with their decision to continue a pregnancy. Lazarus and Folkman [1984] define coping as the thoughts and behaviors used to manage the demands of the stress (the diagnosis). Coping strategies can be divided into task-focused coping, which aims at managing the external environmental aspects of the stressor, and emotion-focused coping, which regulates the internal affective consequences of the stressor. The coping strategies these parents described represent both task- and emotion-focused coping. These strategies allowed parents to cognitively reframe their situation in a way that allowed them to wrestle with their decision emotionally, while still continuing with the remainder of the pregnancy physically. These coping strategies also helped parents work through the stages of grief and adapt to the loss of their "hoped-for child" [Solnit and Stark, 1961].

Many of these coping strategies helped parents gain a sense of control over their situation [Taylor, 1983]. Taylor [1983] describes this process as coping activation, as parents gain a sense of mastery as part of their adaptation. Given the uncontrollability of these parents' situation, as well as the perceived uncertainty of HPE, it is not surprising that parents drew heavily on these strategies. They most likely represent ways that these parents have coped in the past and were successful in allowing them to adapt to a stressful situation.

Other coping strategies that parents described were used to adjust to the changes in the pregnancy that occurred as the result of the diagnosis of HPE. Such was the case in many descriptions of parents' behaviors and cognitions aimed at normalizing the pregnancy.

Chescheir and Cefalo [1992] noted that obstetrical care for women with a diagnosis of a fetal abnormality is often shifted to a tertiary care facility where specialized testing and consultations replace the normal prenatal care. Through normalization, parents could react against these changes in familiar ways and attempt to resume a normal pregnancy.

In contrast, parents' denial or deflection of the diagnosis provided them with a normal defense mechanism that protected them from the overwhelming emotions that accompanied the diagnosis and their decision [Quine and Pahl, 1986]. It is interesting to reflect upon the difficulty some parents had in believing the diagnosis given that all parents had received the diagnosis of HPE by ultrasound. Previous work has shown that inadvertent ultrasound diagnosis can be complicated, given that parents are neither prepared nor expecting a diagnosis via ultrasound, and thus often have strong emotional reactions and can feel backed into the diagnosis [Lorenz and Kuhn, 1989; Green, 1990]. These parents had little preparation, which may have exacerbated a crisis and their subsequent denial of the diagnosis. It may have also heightened their emotional distress and, in turn, ambivalence for the remainder of the pregnancy.

Zuskar [1987] states that, for mothers, prenatal diagnosis of an abnormality can create considerable ambivalence toward the pregnancy. Mothers and fathers both reflected this ambivalence toward the pregnancy in their doubts about their baby's quality of life and their secret wishes that their baby might die during pregnancy. These death wishes have been described as a coping strategy used by other women continuing pregnancies with a prenatal diagnosis of an abnormality [Finnegan, 1993]. Preparations for the baby's death may have intensified these thoughts. Parents were sometimes reluctant to discuss their ambivalence toward their baby's life, as it engendered feelings of guilt and shame and contrasted with their need to be certain of their decision. Parents may benefit from having these feelings of guilt and shame acknowledged, while being granted permission to express their doubt about their decision to continue the pregnancy.

Given this set of factors in the parents' decision-making process, parents described a wide range of informational, emotional, and supportive needs. While these needs are not inconsistent with previous studies [VanPutte, 1988; Palmer et al., 1993; Helm et al., 1998], the depth in which parents described their needs in this study demonstrates that they are not often straightforward.

Parents often described conflicting needs. For example, in the delivery of the diagnosis, many parents mentioned the need to have more specific information about HPE from health care professionals, while simultaneously wanting hopeful information. Given the seriousness and uncertainty of this condition, this is a difficult need to honor and poses an interesting challenge for professionals who may strive to provide honest yet hopeful information. Hope cannot and does not mean creating false expectations. Rather, parents may be asking professionals to take the time to support them

with information that meets their needs. Even when little about their baby's prognosis seems hopeful, perhaps professionals can help parents feel hopeful about their ability to make and carry out the best decision for themselves.

Further complexities can be seen in the parents' descriptions of their needs as they decided to continue the pregnancy. Consistent with previous research, parents describe wanting to be supported to make their own decision about the pregnancy in a nondirective environment [Allen and Mulhauser, 1995; Chitty et al., 1996]. However, once the decision has been made to continue the pregnancy, they asked for support and involvement from health care professionals. The need for neutrality disappeared in parents' minds once the decision was made. Parents discussed wanting professionals to respect the coping strategies they utilized during the remainder of the pregnancy, such as planning and preparations, maintaining hope, and normalization. The experiences many parents described as not helpful were cases where this involvement was lacking, often because parents felt professionals still felt obligated to stay neutral. Perhaps these results suggest a larger challenge to the belief that professional distance and neutrality is helpful for parents involved in reproductive decisions.

And finally, given that the decision to continue the pregnancy is a subtle process that affects the remainder of the pregnancy, many parents described their needs throughout the rest of the pregnancy to include continued support from professionals and family and friends. This reinforces the importance of social support in adaptation to an adverse event [Taylor, 1983]. The challenge, however, is finding ways to help parents garner support to optimally meet these continued needs. Many parents described how words or gestures consistent with the ways they were already coping with their decision were the most helpful. For example, one mother who described needing to stay hopeful for a miracle said she found it most helpful for others to support that need and be hopeful with her. In contrast, feelings of isolation and lack of support occurred when professionals, family, or friends did not understand how parents were feeling and provided support in ways that conflicted with their needs. Thus, an understanding of parents' beliefs and perspective is a first step in beginning to help parents facilitate gathering social support.

Study Limitations

There are several important limitations to this study. The results from this study were exploratory and represent only the experiences of this sample of parents continuing a pregnancy with HPE. The small number of parents in the study limits the ability to quantify responses within categories. Also, the reasons that parents declined to participate in the study are unknown. Nonparticipants may have had discrepant experiences. Although the sample consisted of parents recruited from a wide variety of resources, these parents were connected to HPE medical and support groups, which may make them similar in their experiences and needs. Most

parents were Caucasian and predominantly middle class, and thus limit these results to a certain socio-demographic group.

The retrospective nature of the study also imposes a limitation. Parents in this study discussed a diagnosis that occurred as recently as 6 months to as long as 12 years ago. However, many parents for whom it had been some time since the diagnosis stated that they could easily go back to the moment and feelings surrounding the diagnosis of their child's HPE. Thus, the degree of accuracy in recall may be high because of the highly emotional nature of the diagnosis and its imprint on the parents' memory. Despite these limitations, this exploratory study successfully identifies areas for additional research.

Implications for Health Care Professionals

This research suggests several challenges for health care professionals in working with parents continuing pregnancies with a diagnosis of HPE. At the core of these challenges is the need to clinically overcome the isolation from the medical profession that many parents described. This isolation was often the result of feeling that health care professionals stepped back from the parents' decision. Although health care professionals may feel that this stance is supportive of the patient's autonomy, it is clear that once these parents seem to be on a path to continue the pregnancy, they sought support of their decision. Parents indicated that they needed and wanted health care professionals to support their decision to continue the pregnancy. If they are unable to provide support, professionals should refer parents to those who can support them.

Health care professionals should not avoid discussing the difficult issues that parents face when making a decision to continue a pregnancy following the diagnosis of an abnormality. Interventions aimed at understanding the parents' experiences and needs are essential to dealing with parents' isolation. Health care professionals should make themselves available to parents not only by meeting their needs medically, but also by providing counseling from the time of diagnosis and throughout the remainder of the pregnancy. Specifically, health care professionals can:

1. Begin a discourse with the family regarding the meaning of the diagnosis, medically and emotionally for both the parents and the affected child.
2. Provide anticipatory guidance for parents regarding pregnancy options.
3. Anticipate parents' fears regarding the reaction to their decision by health care professionals, family, and friends.
4. Help parents negotiate their way through additional medical visits by helping them plan and foresee the range of possible needs for the baby, including preparing for possible death or birth of a child with urgent medical needs.
5. Refer family to support resources (disease support groups, families with children with a similar condition, support groups that support their pregnancy decision, clergy).

6. Work with parents as they begin to cope with their decision in an attempt to enhance their adaptation over time.

Further prospective research needs to be done to examine parents' decision-making process following the prenatal diagnosis of a fetal abnormality. Specifically, this research can aim to develop intervention tools that can assist professionals in helping parents meet their informational, emotional, and supportive needs. These tools can help decrease parental isolation and increase social support.

In summary, the decision that parents made in continuing their pregnancy evolved over time and consisted of several factors. This process has not previously been described in this population, especially the notion that most parents revisit their decision to continue the pregnancy throughout the remainder of the pregnancy. This study illustrates that the decision to continue an affected pregnancy is complex and cannot be ascribed to a one-time choice. An awareness of the subtle, more passive aspects of such a decision provides a framework in which to understand the experiences and needs of parents after the prenatal diagnosis of an abnormality.

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