

1-1-2003

Stories of Mothers of Medically Vulnerable Infants

Sarah E. Davis
San Jose State University

Follow this and additional works at: https://scholarworks.sjsu.edu/etd_projects



Part of the [Maternal, Child Health and Neonatal Nursing Commons](#), and the [Pediatric Nursing Commons](#)

Recommended Citation

Davis, Sarah E., "Stories of Mothers of Medically Vulnerable Infants" (2003). *Master's Projects*. 845.
DOI: <https://doi.org/10.31979/etd.a4np-q4pu>
https://scholarworks.sjsu.edu/etd_projects/845

This Master's Project is brought to you for free and open access by the Master's Theses and Graduate Research at SJSU ScholarWorks. It has been accepted for inclusion in Master's Projects by an authorized administrator of SJSU ScholarWorks. For more information, please contact scholarworks@sjsu.edu.

Stories of Mothers of Medically Vulnerable Infants

Sarah E. Davis, RN, BS, MS

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

Susan O. Murphy, RN, MS, DNSc

Professor, School of Nursing

[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

This research was supported in part by a grant from Sigma Theta Tau, Alpha Gamma Chapter. The first author wishes to acknowledge the mothers who willingly shared their experiences and Dr. Kathy Abriam-Yago who validated the results of this study.

Correspondence concerning this article should be address to Sarah E. Davis, [REDACTED]

[REDACTED] E-mail: [REDACTED]

As medical technology advances, more and more medically vulnerable infants are sent home to parents who may be unprepared to care for their complex medical and developmental needs. The caregiver (usually the mother) must assume a specialized role that includes not only the expertise of “mother”, but also expertise in her child’s illness, expertise in navigating the health care system, and expertise in finding and using medical, financial, and emotional resources.

The transition from the relative safety and support of the NICU to bringing the baby home can be difficult for parents. While staff see the infant’s condition as stable, the mother may continue to feel unprepared and inadequate as a caregiver (Affonso et al., 1992; Bruns, McCollum, & Cohen-Addad, 1999). Nevertheless, once the child has been discharged, the parents must take on a “quasi-professional” role (Manns, 2000). They become specialized caretakers as they carry out medical and health tasks previously performed by the NICU staff (Leonard, Brust, & Nelson, 1993; Odom & Chandler, 1990; Pearl, Brown, & Myers, 1990).

Therefore it is important that health care providers who provide services and interventions for medically vulnerable infants and their families understand the needs of parents as they assume responsibility for their infant. With a better understanding of the parent’s own perceptions of their needs, interventions and services can be refined or expanded, easing the parents’ transition to the responsibility of caring for their infant.

To increase that understanding, a qualitative interview study was undertaken. Mothers were the informants in this study because they are generally the primary caregivers and are thus responsible for the day-to-day care of their medically vulnerable infants.

Method

Sampling

A purposive sample was drawn from a Public Health Department program for medically vulnerable infants and their families. To be eligible to participate in the study, mothers had to be over the age of 18 and have a medically vulnerable infant less than one year of age. Medically vulnerable infant was defined as an infant having required an NICU stay of greater than 28 days and having an underlying or chronic condition that caused, or put the infant at risk for, future health problems and developmental delays. The mothers also had to speak either English or Spanish as their preferred language.

Five mothers were interviewed for this study. The mothers' ages ranged from 19 to 38 years. Their educational levels ranged from completing 5th grade through completing graduate school. Two of the mothers were white and three were Hispanic. Two mothers spoke Spanish and three spoke English. For three of the families, this was their first child. One family had two other children; the other had three.

There were six infants, including one set of twins. At the time of the interviews, the five boys and one girl, ranged in age from 4 months to 11 months. The youngest infant's adjusted age was 1 month. Throughout this article, for ease of reading and to maintain confidentiality, the infants will all be referred to as "he". For the same reason, the twins will be referred to as one baby, unless clarity dictates otherwise.

The infants had a variety of underlying conditions. Three were premature. Other conditions included brain abnormalities ranging from mild hydrocephalus to cerebral dysgenesis and microcephaly. Three infants had abnormal facies and genetic syndromes. One infant had metabolic abnormalities. One infant had laryngomalacia. Two had cardiac problems, including

VSD, PDA, coarctation and hypoplastic aortic arch. Two were gastrostomy tube (GT) dependent. Four had reflux. Two infants had kidney abnormalities. One infant had bilateral hip dysplasia.

Data Collection

IRB approval was obtained from both the Public Health Department and the university's review board. Prior to the interview, written consent was obtained. If the participant could not read, the consent was read to her. Each participant received a copy of the consent. Every effort was made to emphasize the voluntary nature of participation.

Individual interviews were conducted in each participant's home. Because the researcher herself is bilingual, all communication, whether written or verbal, was in the participants preferred language of English or Spanish. Interviews were audiotaped and field notes were taken during the interview. The same researcher conducted all interviews.

The intent of this research was to allow the mothers of medically vulnerable infants to speak for themselves. The mothers were invited to "tell the story" of themselves and their baby. They were invited to begin at whatever point they wished. All chose to begin with their pregnancy. Participants were encouraged to tell what it was like, or is like, for them to be the mother of a medically vulnerable infant. Probing questions such as, "Were there things that made it harder or easier?" were used to draw out information. The interviews lasted 20-50 minutes, continuing until the participant stated she had finished.

Data Analysis

Interviews were transcribed verbatim. A bilingual native Spanish-speaker transcribed the Spanish interviews and translated them. Because a direct translation doesn't always convey the underlying meaning of a statement, the researcher also reviewed the English translations while listening to the Spanish tapes.

Data analysis began with line by line coding, looking for meanings. To be sure the meanings came from the mothers, the researcher repeatedly returned to the transcripts and occasionally replayed parts of the tapes.

The researcher then reviewed these codes with a co-researcher, comparing codes across interviews to find common themes. The mothers' own words were used whenever possible to retain and convey the original meanings. To exemplify the themes, representative quotations were selected. Throughout the process, rather than fitting the mothers' statements into categories, the researcher allowed the meanings of the mothers' statements to define the themes.

Findings

As with any new baby, a medically vulnerable infant must be incorporated into the life of the family. The work of this transition is principally the work of the mother as primary caretaker. The mother considers what it will mean to have this infant in the family, how he will fit in, and what things will change. The mother wonders about how his personality will unfold and what his future will bring. She thinks about her role as a mother and how to best meet her child's special needs. With a medically vulnerable infant, a mother also has to consider the implications of health and developmental problems. She has relationships with multiple health care professionals who are now a part of her family's life. The mothers in this study touched upon all of these matters. They seemed to be exploring and grappling with three overarching issues: a) the infant and his future, b) navigating relationships with health care professionals, and c) discovering what it means to be the mother of this child.

The Infant and His Future

Reframing normalcy and finding acceptance: "I didn't want my child being lumped in..."

Each child had characteristics outside the range of what would be considered ordinary or normal by other parents or health professionals. The infants' problems ranged from extreme prematurity to multiple physical anomalies to documented cerebral abnormalities. These conditions put the infants at risk for cognitive and developmental delays. Nevertheless, the mothers repeatedly referred to their children as normal and seemed to want others to see the infants in the same way.

One mother struggled a great deal with how to think about her child's test results that were just outside the range of normal. She consciously chose to see the difference as insignificant, yet health care providers repeatedly brought her attention to it as something that might require surgical intervention at some point. Initially, on their doctor's advice, this couple chose not to tell anyone else about the potential problem. The mother said:

I realize now that what we did was we didn't tell anybody who actually [had contact with the baby]. . . . So, we sort of insulated our existence by keeping all the people who were coming into contact with him in a happy little denial. Not denial, but, like, this was just a normal – like, just everybody excited to see the baby. Now it sort of permeates every conversation we have. And that is exactly what we didn't want it to do. We didn't want it to dominate. . . . We didn't want it to become a stigma, you know.

Another mother said, "If my baby is not like everyone else, he is going to suffer, and I will suffer to see what he is going through, what he is feeling, everything."

Mothers sometimes completely reframed normalcy. Mothers stated that their infants' health and development were normal even when problems were obviously apparent. One mother,

whose infant had reflux and was GT dependent, stated, “Despite everything . . . so far he hasn’t been sick with anything. Nothing. He has been very healthy.” Another mother strongly disagreed with the professionals’ view of her infant with brain dysgenesis and multiple anomalies:

A lot of people tell me, “Oh, he isn’t a normal baby,” like the doctors. . . . But I just ignore them. And I’m like, “He’s a normal baby for me.” ‘Cause he does all what a baby does. I mean, maybe he doesn’t do it on time, but he is trying to get there.

By reframing normal, the mothers seemed to convey an underlying acceptance of the way their baby is and the way things are. While they acknowledged the infant’s limitations, they focused on how their infant could be seen to be just like any other infant.

One infant was severely developmentally delayed. At 11 months of age, he didn’t roll over, crawl, or sit. He could only move his hands and turn his head. His mother focused on how she and her husband accepted their baby and treated him as they would their other children.

In the beginning it was very hard, because [my husband] didn’t accept [the baby], because, well, he didn’t expect him to be sick like this. But . . . he began to change. He started to get closer to him, and now he adores the baby. He calls me on the phone and tells me, “Put the baby on.” And then he talks to him and the baby opens his eyes. . . .

When we go to the store, he takes [the baby] out so that people can see him. He says that he’s very happy with his baby.

Another mother was torn by grief because her 7 month old baby, who is microcephalic and GT dependent, resembled her first child who had died in infancy. She said, “Why has this happened to me?” and “I can’t accept this.” Yet, at the end of the interview, she said, “I didn’t say anything about how bright he is, how he is, how he smiles, and sucks on his fingers and

toes.” Then she demonstrated how he was just beginning to sit unassisted. She said, “Despite everything, we love him very much.”

The baby overcoming: “He’s trying his best to come along.”

The mothers seemed to see their infants as overcomers. They described their infants’ inherent strengths and their apparent will to survive, even prenatally:

When I was pregnant, it was hard, ‘cause I really wanted a baby. But then when they told me he was gonna have those kind of problems, everybody started telling me, you know, get an abortion. But I didn’t wanna, ‘cause he was already moving inside of me. . . . And it’s weird, ‘cause every time a person would tell me, “Oh, get an abortion,” the baby would move inside my stomach, like saying, “No.”

Mothers focused on fundamental accomplishments, such as breathing and eating. One mother described her infant’s birth: “All I kept focusing on, . . . was that he was breathing on his own. And I thought, ‘OK! We’re good!’ I thought, that’s the big hurdle. If he’s breathing on his own, you know, it’s smooth sailing from here.” Another mother described her infant’s response to a nasogastric (NG) tube:

He pulled it out. [Laughs.] He used to pull it out a lot, so I called the public health nurse and told her that he was just pulling it off. She said, “Well, don’t put it back in. Let’s see if he eats.” And he started getting the bottle.

Mothers also talked about their infants needing fewer medications and having fewer appointments:

Right now he is on three medications. He had seven medicines and he is down to 3, so I’m happy. Yeah, he still has a lot of appointments. Not like before, though. He has [one] probably [every two weeks] or once a month.

One mother felt that her infant had overcome so much that the rest of the world should know about it:

When he's bigger, I think I'm going to take him on TV so that people can see him, so that they can see all that he's gone through. Because when he was gravely ill, the ambulance came and took him to [the hospital] and the baby looked dead. His eyes were open and he had a machine to breathe because he almost couldn't breathe anymore. [But] I still have him, thanks to God.

Navigating Relationships with Health Care Professionals

Receiving support and reassurance: "They made you feel pretty comfortable."

All of the mothers mentioned finding support and reassurance in their interactions with health care professionals, both in the hospital and at home. Mothers spoke of receiving help from several sources: from doctors, nurses, social workers, and early intervention specialists.

Competence and professional expertise were clearly important to these mothers. One mother was concerned that her infant was too small to have heart surgery. She brought that up in a discussion with the surgeon:

But the surgeon said, "Oh, I do them all the time. And all my patients are two pounds. So it's OK." I'm like, "OK . . . that seems a little small to me. [Laughs.] If you say you're used to this size, I'm OK with it."

One mother mentioned that the NICU Nurse Practitioner (NP) and the neurosurgeon made her feel reassured. She also spoke of the Public Health Nurse (PHN) who visited in the home: "I thought she was very knowledgeable and I was reassured just having a nurse here, doing the things we talked about once I left the NICU." Another mother commented on the knowledge and skills of the bedside nurses:

You get these nurses who have twenty odd years of experience, at least the ones that had this boy. They had a ton of experience. Especially initially, the really experienced nurses took him. Some of them really want the sick ones, 'cause they are a challenge.

The 19-year old mother appreciated the emotional support of the hospital social worker: If I had any problem, I would tell them and I would feel good about myself. 'Cause there is, like, somebody that could hear me and I don't have to go to a family member and tell them all my stories and everything.

Another mother described the physical and emotional support she received at home:

Well, thank God I have [the regional center's] support. They give me hours so that I can rest. . . . [The home therapists and the PHN] come, they give him some therapy and we talk . . . and they tell me they like to see me like this, laughing. Before, they said I was more depressed. I was always very tired, not now, a little bit less.

Seeking and weighing professional information: "It's kind of a double-edged sword."

Another aspect of the mothers' relationships with professionals revolved around getting information. Even during pregnancy, the mothers wanted to know the whole story of their babies' conditions. One mother, whose baby had genetic anomalies, suspected that information was being withheld from her:

When I went to the clinic, well, I would tell the doctor [that I was uneasy] and she'd say, "Not all pregnancies are the same". . . . I felt when they were doing the ultrasound that something was not right. Because I would say to them, "Is it OK?" They would tell me, "Well, everything looks fine." About the [previous ultrasounds], they would tell me, "Everything is perfect. Everything is good."

When parents did receive information, they had to weigh the seriousness of it and how it applied to their baby. One mother became frustrated with hearing about potential complications for premies such as her infant:

You are constantly worried the whole time you are there 'cause they tell you about they can get NEC [necrotizing enterocolitis], they can get an infection, they can get this, they can get that. And you're like, "Is it ever gonna stop with you people scaring me?" I know they don't want you to be surprised if they have bad eyes or if they get NEC or something, but it gets kind of tiring. . . . Yeah, it's kind of scary, 'cause [the doctor is] thinking of everything under the sun that can be wrong.

Yet she acknowledged her contradictory desires:

I prefer to know everything, but sometimes it's like they were making something out of nothing, just because they were looking. . . . I don't wanna know everything if there is really nothing wrong.

Even when actively seeking information, mothers were ambivalent. This mother described seeking another opinion regarding surgery for her son:

The good thing about getting another opinion is, if they concur, then you feel more confident. The bad thing about getting another opinion is that the more opinions you get, the more complicated your decision is going to become. So there's that risk. You need to know about that.

One mother mentioned that even passing remarks by someone "in the position of authority in the situation" made a lasting impact on how she viewed her son and his situation:

The different things that [professionals] have done, whether they were conscious, like taking the initiative to take me down and show me the films, or just routine, such as the

kind of language that the neurosurgeons used in the course of just laying out the picture for us, or completely, you know, haphazard, like the comment that nurse made. . . .

.When you are the parent . . . you sort of hang on all that. You know, you really hang on every word, on every innuendo, “What did he mean by that?”

Making decisions: “I knew they meant the best, but... ”

The mothers didn’t always immediately agree with their health care providers’ treatment plans. Often the mothers balked at invasive procedures. One of the mothers was frustrated with the number of tests given to her infant. She described a kind of struggle for control over what was happening to her child:

You feel like you don’t have a lot of control when you’re there. And initially you’re kind of scared, so it’s good that they’re in control. I wouldn’t know how to raise a fetus anyway. So [laughs], it’s better that they raise it. But, eventually, when they turn into babies, it’s really frustrating. ‘Cause then they’ll do tests and usually they’ll let you know, . . . but sometimes they would have already done the tests. Or they would have already scheduled it and they sort of casually tell you that they are doing it. And you’re like, “Can you ask my permission first?” I think it’s just they are so used to testing the babies all the time that maybe they don’t think they should ask your permission.

Two of the mothers initially refused to allow a gastrostomy placement. Yet, with time, they came to accept that it would be the best course of treatment for their infants. One of these mothers said:

I would tell them, “No, just leave him that [NG tube] in his nose.” And they would tell me, “He’ll vomit again.” “No, maybe not, God willing.” But he always vomited. Until

one time . . . I saw the tube here, that went through here [back of throat] and I saw it, and I said, “No, no, no.” I said, “I’m going to have him hospitalized to have the surgery.”

One mother, who herself is a health care professional, accepted a treatment plan which included surgery: “I don’t want my baby to have surgery. But as soon as they said, ‘We think the prudent thing to do is not wait any longer,’ I’m on that track with the docs. I’m on that.”

Discovering What It Means to Be the Mother of This Child

Fears and worries: “It’s kind of scary.”

Most of the mothers reported that at some point they were worried about losing their child. The mother of twins, whose infants had been home from NICU for about two months, cried when she thought back to the possibility that one or both might have died. Another mother reflected on how much her life would change if her infant were to die:

They told me that he was in critical condition. And I felt very bad. I thought, “If I lose him, what am I gonna do without my son?” But, no, everything came out good, and he is here. Right now that I look at him, I think, “What am I gonna do if he ever leaves? Like, how am I gonna feel without him?” So, I’m used to him, and I’m just so used to him.

Several mothers were reluctant to allow their infants to have surgery, fearing the real risk of the infant not surviving the surgery itself.

Mothers also worried about their infants’ health and development and the uncertainty of the future. One mother described her worries during her infant’s NICU stay:

You figure until the day he goes home, something bad could happen. And actually, he’s not out of the woods for NEC until he is, like, 35 weeks or something. Even then, he could still get it. And you’re like, “Are you kidding me? I have to wait that long?” Yeah,

so that was no fun. And then the retinopathy, you know. I had to wait until just last week. [That's] when he was finally cleared.

Another mother wondered about her child's cognitive development: "I kept asking myself, 'How is it going to be? How will he develop?' Because they told me at the hospital that they didn't know, because he was so small [so young], and no one knew."

When it came time for discharge from the NICU to home, the mothers were fearful. One mother expressed it this way:

[The nurse] called me at home and said, "We're thinking of sending him home on Friday." And I'm all, "You mean this Friday?!" She said, "Yeah." And I'm like, "Are you crazy?!" She said, "No, he'll be fine." And I'm like, OK. She really meant it, but I'm like shakin' in my boots, because it was so upsetting. I guess in hindsight, it's probably better it happened that way. If I'd had too much time to think about it- "Oh, my God. He's coming home." I don't know.

The mothers felt ambivalent about bringing their infants home, fearing the responsibility and questioning their own ability to meet the infants' needs.

The time arrived when we were going to bring him home. I said, "It's going to be very difficult. And with my other children, how will I manage to take care of him. . . . He'll have to be watched every day, all the time". . . . Well, the day came when we were going to bring him [home]. . . . I said, "How am I going to manage? How am I going to manage with my baby? What if at home, I don't know, something happens to him?" I felt that he was better at the hospital, but at the same time, I wanted to have him home.

Rising to the challenge: "I'm going to do everything that's in my power."

Although the mothers had fears about caring for their infants at home, paradoxically they saw themselves as very important to the babies' health and well-being. They believed they could offer what no one else could. One mother said, "I take care of him. Wherever I go, he goes. I never leave him with anybody."

The mothers spoke of meeting their infants' needs in a variety of ways. Several mothers described managing their child's health: keeping all appointments, getting immunizations, and giving medications.

When he's due [for a feeding], I have to be thinking, "It's almost time for his milk and I have to give him such and such medicine." Sometimes I forget and I give it to him on the next feeding. But I always give it to him . . . because that's what makes him well.

Basic baby care required learning special skills. The mothers actively assumed the challenges of meeting their infants' unique needs. One mother described feeding her infant when he first came home from the hospital:

I came home and I put him in his crib and I started fixing his milk. But I was nervous, 'cause he came with the NG tube, so I had to hang the syringe on the top of the crib or hold it there while he was feeding.

The mother of a baby with a GT tube was afraid that manipulating the tube would hurt the baby. She related how her husband helped with GT care until she could bring herself to do it:

It was a bit difficult to feed him, but, well, this passed in about two days. After, I could clean his stomach. Because at first, it was my husband that cleaned him. He would tell him, "I'm going to be your nurse. I'll take care of you."

At times, mothers expressed the conviction that they were better able to manage their infants' care than anyone else. One mother felt vindicated in refusing hospice care and keeping her baby at home, because he ended up exceeding the doctors' expectations for his lifespan:

They told me that I could take the baby to a place and leave him there and just go visit him whenever I wanted and to wait for him to die. My husband and I told him, "No, no, no. The baby is going to stay at home." Because they said that why would we want to have him if he wasn't going to live? They told me that about six months ago. . . . And if you see him, the baby looks really good.

Lavishing love: "I do adore my son."

The mothers also talked of giving more than merely physical care. They spoke of meeting their infants' emotional needs by holding them, playing with them and entertaining them. These acts of loving were displayed from the very beginning:

We got to do skin to skin [cuddling the infant against one's bare chest] from a pretty early point, which initially was a little scary, 'cause he was pretty small. We were holding this little scrawny little thing. It was good. I figure, maybe it helps him to be held.

Love and nurturing were powerful forces in the infants' lives: "Lately even the doctors have said that he has changed a lot. They ask me what I have been giving him. And I told them, 'Nothing. Only love and his milk.' [Laughs.]" When considering the uncertainty of her baby's future, this same mother said, "All that is left to do is to take care of him and give him love and attention, which is what they need."

The mothers seemed to feel that their very presence was necessary for the infants to fare well. One mother related her impatience to get out of the hospital after delivery so she could be with her baby who had been transferred to another hospital. Sometimes the need to be with their

infant overrode all other relationships and responsibilities: “Everyday we were going to see him [at the hospital], and we were also neglecting our other children,” and

When he was in the hospital and I would come home, I would cry because I would leave him. My husband would say, “It’s not good for you. Don’t cry so much. Remember that you have another child to take care of.”

All of the mothers indicated commitment to love and care for their babies with the intention they progress and thrive to the greatest extent possible:

Thanks to God, I have been able to do well with him. Well, the doctors told me that he could die. But here I have my son with me, with lots of love and care. And my baby is doing well, thanks to God.

Another mother expressed it this way: “I tell myself he’ll be with me always. I think he’ll be with me always.”

Discussion of Findings Related to the Literature

There are many studies in the literature about the stress of having an infant in the NICU (Affonso, et al., 1992; Miles, Holditch-Davis, Burchinal, & Nelson, 1999; Seideman, et al., 1997) and the subsequent pediatric caregiver and family burden (Fleming, et al., 1994; Glasscock, 2000; Leonard, et al., 1993; Manns, 2000; May, 1997; May & Hu, 2000; Patterson, Leonard, & Titus, 1992). Prior to beginning this study, the first author anticipated hearing about parents’ needs and desires for support or services. However, while the mothers in this study all voiced worries and fears regarding their babies and mentioned a multitude of medications, treatments, and appointments, they did not focus on that aspect of their experience.

When discussing their interactions with health care professionals, the mothers’ experiences reflected findings in the literature. The mothers described desiring and receiving

support and reassurance from professionals (Beal & Quinn, 2002; Cescutti-Butler & Galvin, 2003; May & Hu, 2000; Tomlinson, Swiggum, & Harbaugh, 1999; Van Riper, 2001), seeking and weighing professional information (Bass, 1991; Beal & Quinn; Diehl, Moffitt, & Wade, 1991; Hurst, 2001a, 2001b; Swallow & Jacoby, 2001; Tomlinson, et al.), and making decisions (Thomas, 1987; Tomlinson, et al.).

In coming to accept and understand their infants, mothers in the current study *reframed normal*: they redefined normal to include their children. This reframing is not the same as the more frequently described concept of normalization, which is usually about trying to make the child and the situation as normal as possible (Callery, 2001; Deatrck, Knafl, & Murphy-Moore, 1999; Johnson, 2000; Knafl & Deatrck, 2002; May, 1997). Rather, by describing their infants as normal, these mothers expressed acceptance of the infants just as they were, although they were well aware of their infants' disabilities and limitations. This is similar to Johnson's (2000) study of mothers' perceptions of parenting children with disabilities, in which mothers were quoted as saying, "I don't think of her as different," and "I try my best to ignore the disability." However, in Johnson's study, mothers do not seem to actually characterize their children as normal.

Also of note in the current study was the mothers' view of their infants as *overcomers*, as being agents in their own survival and progress. In their study of mothers whose children suffered brain injuries, Guerriere and McKeever (1997) found that the mothers regarded their children as exceptional, using descriptors such as extraordinary and fighter. Kearney and Griffin (2001) also found that parents of disabled children described their children as fighters, survivors, and gutsy.

As stated earlier, parental fears and worries have been studied extensively. Less common are studies describing mothers as rising to the challenge of caring for a medically vulnerable

infant. Mothers in the current study expressed willingness to do whatever was necessary to care for their infant, even when they found it difficult. Three other studies touched on this dimension. Mothers in Guerriere and McKeever's (1997) study accepted their children's injuries and the consequences and "moved on." Kearney and Griffin (2001) described the concept of defiance: that parents exhibited positive, action-oriented behaviors that allowed them to function with hope and optimism. Eakes, Burke and Hainsworth (1998) describe having a "can do" attitude as an effective internal management method for chronic sorrow.

Similarly, much has been written about the emotional and physical burdens of parenting a child with disabilities, but there is little literature about the positive experiences of these families. Kearney and Griffin (2001) state that the tragedy, burden, and pain of having a disabled child are assumed in the nursing literature. They contend that professionals focus on the negative, rather than acknowledging that many families manage their lives cheerfully and that parents derive joy from their children. Mothers in the current study also seemed to find joy in their infants as they expressed their deep love and commitment.

Conclusion

The mothers in this study actively took on the role of caring for their medically vulnerable infants. Contrary to most findings in the literature, the mothers didn't focus on their stress or burden. Instead, while they didn't minimize their additional responsibilities or worries, the mothers rose to the challenge of meeting their infants' special needs and saw their infants as overcomers as well. They demonstrated their acceptance of their infants by reframing normal to include their own infant and by giving the infants committed love and attention.

This shift in focus has implications for nursing care. In the NICU and in follow up care, nurses should plan interventions that draw on parents' strengths, rather than focusing primarily

on stress and coping. The mothers in this study revealed their strengths and their determination to move forward. Even though they were reluctant to allow invasive procedures or to perform “technological” care, when they became convinced it was best for their baby, they accepted and did whatever was necessary; they rose to the challenge.

Because this is a small study, the results cannot be generalized. However, four themes stood out which have not been explored extensively in the literature. Several studies mention normalizing and viewing the world through a “normalcy lens”, but the separate concept of completely reframing normal seems to be new. The infant as an agent and overcomer also seems to be a new theme. Additional research could show whether these concepts are unique to the women in this study or whether they are more universal. Researchers might also further investigate mothers’ perceptions of their medically vulnerable infants and how that influences mother-infant interaction and infant growth and development.

The themes of rising to the challenge and lavishing love seem to fit in with a growing body of research that looks at the positive aspects of parenting a disabled child. Additional research should explore these themes further. If we intend to provide family centered care, both in the hospital and at home, we need to take into account the positive as well as the challenging experiences in the lives of families with medically vulnerable infants.

References

- Affonso, D. D., Hurst, I., Mayberry, L. J., Haller, L., Yost, K., & Lynch, M. E. (1992). Stressors reported by mothers of hospitalized premature infants. Neonatal Network, 11(6), 63-70.
- Bass, L. S. (1991). What do parents need when their infant is a patient in the NICU? Neonatal Network, 10(4), 25-33.
- Beal, J. A. & Quinn, M. (2002). The nurse practitioner role in the NICU as perceived by parents. The American Journal of Maternal/Child Nursing, 27(3), 183-88.
- Bruns, D. A., McCollum, J. A., & Cohen-Addad, N. (1999). What is and what should be: Maternal perceptions of their roles in the NICU. Infant-Toddler Intervention, 9(3), 281-98.
- Callery, P (2001). Families with parents and children living with HIV described strategies to meet 3 common goals for normalization. Evidence-Based Nursing, 4(3), 92.
- Cescutti-Butler, L. & Galvin, K. (2003). Parents' perceptions of staff competency in a neonatal intensive care unit. Journal of Clinical Nursing, 12(5), 752-61.
- Deatrick, J. A., Knafl, K. A., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. Image – the Journal of Nursing Scholarship, 31(3), 209-14.
- Diehl, S. F., Moffitt, K. A., & Wade, S. M. (1991). Focus group interview with parents of children with medically complex needs: An intimate look at their perceptions and feelings. Children's Health Care, 20, 170-178.
- Eakes, G. G., Burke, M. L. & Hainsworth, M. A. (1998). Middle-range theory of chronic sorrow. Image – the Journal of Nursing Scholarship, 30(2), 179-84.
- Fleming, J., Challela, M., Eland, J., Hornick, R., Johnson, P., Martinson, I., et al. (1994). Impact on the family of children who are technology dependent and cared for in the home. Pediatric Nursing, 20(4), 379-88.

Glasscock, R. (2000). A phenomenological study of the experience of being a mother of a child with cerebral palsy. *Pediatric Nursing*, 26(4), 407-10.

Guerriere, D. & McKeever, P. (1997). Mothering children who survive brain injuries: Playing the hand you're dealt. *Journal of the Society of Pediatric Nurses*, 2(3), 105-16.

Hurst, I. (2001a). Mother's strategies to meet their needs in the newborn intensive care nursery. *The Journal of Perinatal & Neonatal Nursing*, 15(2), 65-82.

Hurst, I. (2001b). Vigilant watching over: Mother's actions to safeguard their premature babies in the newborn intensive care nursery. *The Journal of Perinatal & Neonatal Nursing*, 15(3), 39-57.

Johnson, B. (2000). Mothers' perceptions of parenting children with disabilities. *The American Journal of Maternal/Child Nursing*, 25(3), 127-32.

Kearney, P. M. & Griffin, T. (2001). Between joy and sorrow: Being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-92.

Knafl, K. A. & Deatrick, J. A. (2002). The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing*, 28(1), 49-53, 56.

Leonard, B. J., Brust, J. D., & Nelson, R. P. (1993). Parental distress: Caring for medically fragile children at home. *Journal of Pediatric Nursing*, 8(1), 22-30.

Manns, S. V. (2000). Life after SCBU: The long term effects on mothers at home with a child with bronchopulmonary dysplasia and on home oxygen. *Journal of Neonatal Nursing*, 6(6), 193-196.

May, K. M. (1997). Searching for normalcy: Mothers' caregiving for low birth weight infants. *Pediatric Nursing*, 23(1), 17-20.

May, K. M. & Hu, J. (2000). Caregiving and help seeking by mothers of low birthweight infants and mothers of normal birthweight infants. Public Health Nursing, 17(4), 273-279.

Miles, M. S., Holditch-Davis, D., Burchinal, P., & Nelson, D. (1999). Distress and growth outcomes in mothers of medically fragile infants. Nursing Research, 48(3), 129-40.

Odom, S. L. & Chandler, L. (1990). Transition to parenthood for parents of technology-assisted infants. Topics in Early Childhood Special Education, 9(4), 43-54.

Patterson, J. M., Leonard, B. J., & Titus, J. C. (1992). Home care for medically fragile children: Impact on family health and well-being. Developmental and Behavioral Pediatrics, 13(4), 248-55.

Pearl, L. F., Brown, W., & Myers, M. K. S. (1990). Transition from neonatal intensive care unit: Putting it all together in the community. Infants and Young Children, 3(1), 41-50.

Seideman, R. Y., Watson, M. A., Corff, K. E., Odle, P., Haase, J., & Bowerman, J. L. (1997). Parent stress and coping in NICU and PICU. Journal of Pediatric Nursing, 12(3), 169-177.

Swallow, V. M. & Jacoby, A. (2001). Mothers' evolving relationships with doctors and nurses during the chronic childhood illness trajectory. Journal of Advanced Nursing, 36(6), 755-64.

Thomas, R. B. (1987). Family adaptation to a child with a chronic condition. In M. H. Rose & R. B. Thomas (Eds.), Children with Chronic Conditions (pp. 29-54). Orlando: Grune & Stratton.

Tomlinson, P. S., Swiggum, P., & Harbaugh, B. L. (1999). Identification of nurse-family intervention sites to decrease health-related family boundary ambiguity in PICU. Issues in Comprehensive Pediatric Nursing, 22, 27-47.

Van Riper, M. (2001). Family-provider relationships and well-being in families with preterm infants in the NICU. Heart & Lung: The Journal of Acute and Critical Care, 30(1), 74-84.