

Fathers Reflect on Their Experiences of the Receipt of a Postnatal Diagnosis of Down Syndrome or Trisomy 21

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Abstract: This exploratory study investigated the experiences of fathers upon the postnatal news that their newborn babies had been given diagnoses of Down syndrome. Thirteen fathers were interviewed about their experiences of immediate postnatal support. Participants had biological children born with Down syndrome and interacted with the western medical community regarding the child's birth. Fathers often experienced the messengers of the news of a postnatal diagnosis of Down syndrome as insensitive and pessimistic. They felt strongly that hospitals should be more prepared, and that medical personnel should have better training for delivering a postnatal diagnosis of Down syndrome.

Keywords: Down Syndrome, Fathers, Postnatal Support

In the United States, approximately 400,000 families have a child with Down syndrome (DS), and about 6,000 babies (one in every 733) with Down syndrome are born each year (National Down Syndrome Society, n.d.). Of these, about 85% are diagnosed with DS postnatally (Skotko, 2005b). The manner in which medical professionals inform parents of the news that their newborn baby has been given a diagnosis of Down syndrome has a profound effect (either positive or negative) on the parent(s). The attitudinal beliefs of the messenger, most often the doctor, have a large effect on how that person delivers the news. Often parents readily recall every detail of how the news was delivered: where they were, what exact words were shared, the affect of the doctor, their own

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initial reactions, and whether or not resources were shared. Skotko (2005a; 2005b) researched the experience of mothers upon the receipt of the news that their newborn babies has been given diagnoses of Down syndrome. Skotko (personal communication, 6 July, 2007) suggested that similar research is needed on the experiences of fathers. This exploratory study adds to the literature by examining the experiences of 13 fathers upon the receipt of the news that their newborn baby had been postnatally given a diagnosis of Down syndrome.

Background

What is DS?

Down syndrome occurs at conception, and is diagnosed before the child's birth about 15 percent of the time (Skotko, 2005b). Down syndrome results from the genetic formulation of three, rather than two, copies of the 21st chromosome. All people with Down syndrome experience some degree of cognitive delay. People with Down syndrome are also prone to certain medical problems such as congenital heart defects as well as hearing and respiratory problems (National Down Syndrome Society, n.d., ¶ 1). Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct, or prevent many of the problems associated with Down syndrome in the future (National Down Syndrome Society, n.d., ¶ 1-12).

Parents' Experiences and Perspectives

Written accounts by fathers in the last 15 years on their experiences about how they felt upon the receipt of the news that their child was born with Down syndrome are few. Berube (1996) wrote about the 1991 birth of his son, Jamie. His reflections of his son's birth resonate with the experiences of many parents whose children were born within the last 15 years. Berube wrote,

James appeared within minutes, an unmoving baby of a deep, rich, purple hue, his neck wreathed in his umbilical cord. "He looks downsy around the eyes," I heard. Downsy? He looks stillborn, I thought. They unwrapped the cord, cut it, and gave him oxygen. Quickly, incredibly, he revived. No cry, but who cared? They gave him an Apgar score of 7, on a scale from 1 to 10. I remember feeling an immense relief. My wife was alive, my second child was alive, at the end of a teeth-grating hour during which I wondered if either of

them would see the end of the day. Down syndrome seemed like a reprieve. Over the next half hour, as the nurses worked on James, and Janet and I tried to collect our thoughts, I realized I didn't know very much about Down's, other than that it meant James had an extra chromosome and would be mentally retarded. I must have looked horribly lost, because through her tears Janet was actually trying to comfort me: "We can handle this," I remember her saying... (p. 6)

Berube (1996, p. 6) continued to reflect,

But could we believe our own hope? Could we meet even the simplest challenges this child might pose? Would we ever have normal lives again?... But now we were going to spend the rest of our days caring for a severely disabled child? Would we have even an hour to ourselves?

Berube's (1996) comments are common concerns that new parents often experience upon the receipt of the news that their newborn has been given a diagnosis of Down syndrome. Dwight (2007) recalled,

Maybe she spotted our look of obvious misunderstanding. So she spelled it out: "The nurse thinks he may have Down syndrome." From where I sit now I can split my life in two. There's the time before we heard those words, and the time after. Before we were probably like most people. We knew we were lucky. We were healthy. Our little boy Timmy, was funny and strong and happy. We had jobs and a loving family. But until we were hit with those words, I don't think we had any idea how fragile that luck can be. I knew nothing about Down syndrome, but had lots of frightening preconceptions. My first thought, even as I nursed him in the hospital, was "How will he get a job?" (p. 4).

Bollinger (2007) described her experience of the receipt of the news when a nurse approached her as a new mother in a hallway outside the nursery window:

I will never forget her exact words. She said, "Your son has some features that make us think that he has Down syndrome." My world stopped. Suddenly the hall that had seemed almost stifling was [now] frozen, an icy chamber. I couldn't move. I couldn't speak. I could say nothing in response. I simply nodded my head and walked back down the hall to my room, where my husband Kris was waiting...The hours after that were a blur of visits. In the back of my mind I kept thinking that the pediatrician was wrong, and that the test for Down syndrome would come back negative. So when we got the blood work back from the lab with a positive result, I was in complete shock and denial. (p. 52)

With the exception of a few studies done recently, overall not much research has been done on parents' experiences when given a postnatal diagnosis of Down syndrome. Studies that have been done thus far have been primarily focused on mothers. Skotko (2005a; 2005b) completed two quantitative and qualitative studies. Skotko's first study (2005a) involved an 11-page survey mailed to 6,125 mothers in Spain. Using the same methodology, Skotko (2005b) surveyed 2,945 mothers in the United States. These two studies by Skotko are the largest scale studies known to date.

Skotko's (2005a) study focused on the reflections of mothers of children with Down syndrome and postnatal support. He explored how the news was delivered, how mothers felt in response to the news, what was said, whether or not medical workers gave resources or referrals for support groups, how mothers felt during and then days following the birth, implications for improvement, etc. He intended to collect data that could be used to improve protocols in hospitals of how the news of a diagnosis of Down syndrome is delivered to mothers. His findings revealed that most mothers experienced their physicians as inadequate and, at times, offensive when delivering a diagnosis of Down syndrome. Mothers in both the United States and Spain reported that their physicians rarely addressed the positive aspects of Down syndrome and that they did not offer enough up to date resources and referrals to parents in general.

Medical Model of Disability

The medical model of disability informs medical professionals' current attitudes about disabilities. The medical model is prominent in the lives of people with disabilities. Medical professionals work as gatekeepers to a variety of government-related services for people with disabilities; for example, social security benefits, health care, housing, assistive technologies, etc. The medical model also informs how a medical doctor will deliver a postnatal diagnosis of Down syndrome.

Saxton (2000) explained that within the medical system's view, disability is defined as a biological problem or limitation. Thus, the social consequences of disability, such as high unemployment and low educational levels of people with disabilities, resulting in low socioeconomic status, are thought to be caused by physiological limitation. A fundamental assumption in the medical view is that greater degrees of disability (defined by medical standards as increased pathology) are associated with decreased quality of life. This view is

often referred to in the disability community’s literature as the medical model of disability. Inherent in this medicalized view is the assumption that the source of any problems related to the disability is then located within the individual or within the individual’s body. The core of the medical view is that disability must be prevented, because people with disabilities cannot function within existing society.

Medical schools tend to use the medical model of disability as a framework for anything related to disability in the medical school curriculum. The medical model is not a progressive stance towards disability related issues; rather, it is norm-based, in that people who deviate from the norm are perceived to be lacking in some way. Perhaps the implications of the medical model indicate medical doctors’ lack of preparation for how they can best relay the news of a postnatal diagnosis of Down syndrome to parents. For example, Ralston (2000) reflected on his experience of medical school:

In general, what I was taught in medical school and in my training is that disability—no matter what its form—is a bad thing and to be avoided at all costs. Lectures or seminars on Down syndrome or other genetic syndromes were geared toward the description of the abnormalities and the efforts that can be made to prevent the problem in the first place; that children with congenital diseases may find their lives to be rich and valuable was hardly recognized, much less stressed. (p. 334)

Rothman (2003) explored how the medical model maintains a pre-eminence among models. A list of models for disability can be split into two categories, individual models and societal models (Figure 1). Although multiple models exist, the focus of this comparison is between the medical model and the societal models of disability. Individual models do not integrate issues of oppression and diversity whereas the societal models do. The medical model as an individual model reinforces and perpetuates the problems of stigma and disability oppression.

Figure 1.
Individual and Societal Models of Disability

	Individual Model	Societal Model
Definition of Model	The individual model locates the problems of disability within the individual that implies an inherent fault or responsibility somewhere within the individual. According to the individual models, people with disabilities were perceived as being imperfect in some way and should be	The societal models place the cause and responsibility of the problems that affect people with disabilities on society itself rather than on the individual (Rothman, 2003, p. 9).

	Individual Model	Societal Model
	changed for the general good of society (Rothman, 2003, p. 4).	
Example Models	The Moral Model- The moral model is generally drawn from the religions that have influenced moral thought through the ages. There are two strands of thought that have influenced much of our thinking today: disability as a punishment for wrongdoing and disability as creating an obligation in others to care for people (Rothman, 2003, p. 5).	The Oppression Model- The oppression model develops the concept that those who are viewed as different and "other" and who are excluded from society are oppressed. Oppressed people are not only stereotyped and disenfranchised: They actually become <i>invisible</i> to the dominant society (Rothman, 2003, p.9).
	The Deficit Model- The deficit model is an early iteration of today's medical model. Those who were imperfect or lacked function or ability were missing something very concrete. Scientific method would develop new methodology for eliminating these deficits (Rothman 2003, p.6).	The Diversity Model- In the diversity model, people with disabilities are seen [as] a group of people in society that share certain qualities or characteristics. Awareness of others who are similar to you is an important resource for identity development, which is grounded in an understanding group as well as individual characteristics (Rothman 2003, p.10-11).
	The Social Darwinist Model- Because of the emphasis on the possibility of change and adaptation that was basic to the deficit model, people with disabilities were at first considered to be in need of such changes. Only the change that would enable the individual to compete with others for survival mattered. Survival in the Darwinist model involved competition for needed resources, such as food, shelter, clothing, and medical care. In Darwin's world, where everyone was concerned about his or her own survival, people who were unable to survive on their own due to disability could be left to their fate (Rothman, 2003, p.7).	The Social Construct Model- Disability, according to the social construct model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transportation systems, from segregated education to excluding work arrangements (Oliver, 1991, pp.30-31).
	The Eugenics Model- Supporter's of eugenics took Darwin's position even further. If only the fit should survive, the eugenacists said, then not only should we abandon those who are "unfit," we should also isolate them from the rest of society	The Feminist Model- Merely being born a woman set a person apart and different from the idealized norm, and less valuable. In some societies, girl babies are aborted, exposed, or given away to orphanages as

	Individual Model	Societal Model
	and above all impede reproduction and thus the continuance of the disability in the next generation. Reproduction in this new view should be limited to the desirable elements of the population only—and people with disabilities were clearly not desirable (Rothman, 2003, p.7).	undesirable. Thus many of the problems that women must address in relation to the dominant (male) society are very similar to those that must be addressed by the disabled people in the dominant “able” society (Rothman, 2003, p.14).
	The Medical Model- The medical model views people with disabilities as lacking in some vital element or function. Disability is viewed as a functional loss. The assumption is that there is a standard, or a norm for what human beings are, how they should look and act, and what they should be able to do. People who deviate from the norm are lacking in some way. When interventions of medical science cannot resolve the problem and enable to return the individual to function within the norm, the person is considered to be permanently flawed (Rothman, 2003, p.8).	

Methods

For this study information was gathered from 13 fathers through semi-structured interviews. Interviews were chosen rather than surveys in order for participants to describe their experiences in their own words. Research participants were recruited using a snowball sampling, beginning with fathers known to the researcher and to various human service professionals and colleagues. Potential participants were contacted by recruitment e-mails and fliers sent to fathers and colleagues. Initial recruitment targeted fathers in the western Massachusetts area and a few potential participants who lived outside of the area. The Massachusetts Down Syndrome Congress (MDSC) assisted by circulating a recruitment letter via their MDSC listserv. To increase diversity, recruitment e-mails and fliers were distributed amongst organizations that serve people of color as well as people of varying economic statuses. Six participants outside of western Massachusetts were interviewed on the phone. Seven participants who lived close by were interviewed face to face. The Smith College School for Social Work provided IRB approval of the study. Data for the study were audio

recorded and then transcribed. The interview guide included demographic and open-ended questions. The length of the interviews ranged from approximately forty to ninety minutes.

Participants

Potential participants were asked screening questions to determine if their biological child had been born with Down syndrome in the United States in the past 15 years. Additionally the father must have interacted with the western medical community regarding his child's birth. A time and place was then set for the interview of volunteers who met the study criteria.

Of the 13 fathers who participated, 12 were married and one was divorced. Twelve of the participants were white. The other identified as Latino. Participants lived in Texas, Wisconsin, Indiana, Connecticut, and Massachusetts. Eight of the 13 participants' children were born in Massachusetts. Two of the participants' children were born at home and the rest were born in hospitals. Participants ranged from twenty-nine to fifty-four years of age, with the average age of forty-two. Eight of the participants had sons who were born with Down syndrome and five had daughters who were born with Down syndrome. Eleven of the 13 participants held a bachelor's degree or higher. Seven participants had other children who were older than their child with Down syndrome. Three participants had children who were younger than their child with Down syndrome—and, the three remaining participants had only one child who had Down syndrome.

Results

Fathers' comments fell into several categories: receiving the diagnosis (messengers and experiences); the importance of congratulations; information, resources, and referrals; emotions; insensitive comments; and recommendations. Additional findings were related to heart surgery for the babies, superstar stereotyping, and fathers' reactions to the interview process.

Receiving the News

The messengers. Nine of the 13 participants recalled specifically what was said when the news of the postnatal diagnosis was delivered. They recalled who delivered the news, how they felt in relation to what words were used, and the tones and affects of the medical professional(s)

they worked with. Fathers also reported that the diagnosis was not always delivered by their obstetrician; the news was sometimes delivered by a nurse, a midwife, or a doctor they had never met before.

One participant remarked that having someone he didn't know give him the news of his child's diagnosis was difficult:

...and then the midwife came in with a doctor who we had never met, and the attending physician, and the midwife said, "we think there might be a chromosome problem" and my wife immediately knew what she was talking about, and she said, "what do you mean?" and she said, "Down syndrome," and then my whole body just went cold. You know, and then the doctor (there is always comedy in all this), but the doctor had this *broooooaad Neeeeew Yoooorrk accent*, and she goes "I don't think it's a problem. I looked at the baby and the baby looks fine. I wouldn't worry about it." And, I was "*okaaaaay, we won't worry about it doc*"—it changed everything.

One participant poignantly explained his perception of receiving the news:

He's dropping a bomb on [you] and that's just what it is. There's no other way to look at it. Everything changes in this split second. It [is] hard to see beyond what you're being told.

A father described how he felt when a doctor gave him the diagnosis at the doctor's office visit after his child's homebirth:

I don't think this [doctor] did a good job in terms of the quote "bedside manner." The breaking the news was poorly done. Very little sensitivity, no plan or strategy for, "this is going to be a walloping message, we're going to deliver, how can we make this easy?" It just felt like it was a typical doctor's visit and it was a bunch of people being seen for this and that....and, "I've got to get on to my next patient, oh and by the way...and then see you later." That was definitely it. [My wife] has a bad feeling about that hospital ever since then, even though we've only been there two times.

Another father described a positive experience of the news being delivered by a doctor who was also a father of a child with Down syndrome. The participant felt supported while he struggled with the news. He explained:

We found out immediately [after he was born.] My wife was going through a regular pregnancy and there were some complications during the delivery, and they decided to do an emergency C-section. So we went to a different room and the neonatologist was there. Well oddly enough, or by God's grace, the neonatologist happened to have a son with Down syndrome! We got back to the room and the two doctors, the neonatologist and the OB GYN, came in together. [They]

asked that the nurse leave. We had no clue that anything like this was a possibility. He was very professional and very courteous and very forthright when he said that, "but it appears as though [your son] might show some markers for Trisomy 21." Which at that point I'd never heard of, then he said, "It's also known as Down syndrome." [That was one of] the times that your world stops or that you can almost hear the echo of the heart beat in your head.

Generally fathers who received the news in an optimistic and hopeful manner reported a sense of feeling supported during the postnatal period. Fathers who had a negative experience reported that they did not feel supported during the postnatal period. A participant described a positive experience of how the news of a postnatal diagnosis of Down syndrome was delivered:

So a doctor came in and said, "I just met your daughter and she's beautiful. I spent some time with her and aren't you so lucky. I've been called here for this reason and I'm going to run some tests, and here is the name of the tests. It is going to take about 48 hours and when it comes back it is going to tell us that your daughter has Down syndrome. I can tell you that because I've been doing this for thirty years. So, let's talk about what that means." And, to this day I thank him for when he said it. It was so wonderful! It wasn't like a lot of the horror stories that I've heard. He did a great job. It hit me like a ton of bricks because I was sort of thinking the completely opposite. I was the one who had a hard time right away but my wife really dealt with it because she sort of already [knew.] It really hit me and I cried my eyes out but not for a long period of time. We held each other for a while. I would say it took me about an hour and I sort of went well, "okay, you know what, this is what we've got, so we play the cards we're dealt and I have a beautiful daughter and I'm lucky." And that was pretty much it, and that was my grieving right there.

The experience. Some fathers reported that the postnatal experience was horrible while others described it as a relatively supportive experience. The manner and tone in which the news was delivered generally set the stage of the entire postnatal experience for fathers. Fathers who were met with optimism and were given relevant resources tended to feel more empowered by the experience, whereas fathers who were met with pessimism and adversity were more likely to feel traumatized and oppressed by the experience.

One participant described his experience of the hospital, "it was just very dark and morbid...we were happy to leave." Another person

explained how he felt after the news was delivered in a pessimistic tone by the doctor:

It turned out to be one of the hardest days of my life...it was weird. I got to say it, was a shock right at first. I just didn't know. It hit me like a ton of bricks. It was a shock and my wife ... started crying right away.

A father reflected on having to go back and forth from having had a home birth to the hospital to contend with medical complications during the postnatal period. "Our experience in the hospital just totally sucked, but the time at home was awesome." He described how the pediatrician determined the diagnosis:

She was like "he doesn't look like he has Down syndrome [and] you guys are [young]," and then the pediatrician is like "he looks fine" and then she looked at his muscle tone and [says] "yeah, this is a little loose" and she kind of poked around, for I don't know how long it was, and at the end she was like "oh, he probably has Down syndrome."

Another father reflected on the impact of having a positive postnatal experience:

The doctor came in and he was a terrific doctor, just fabulous bedside manner. And let us know that he had these concerns and that this is what he's seeing...he did it in a terrific way you know, difficult, but I have nothing but respect for how he handled [it] from that respect.

Congratulations

Fathers who were congratulated on their children's births and fathers who were not congratulated consistently expressed the importance of being congratulated. They often discussed the shift from celebrating to the receipt of a postnatal diagnosis as a strikingly memorable and deeply painful experience. A father reflected on when he first spoke to another father of a child with Down syndrome: "I was surprised and he said, 'Congratulations!!!, Which was the coolest thing anybody had said" (he started crying).

Another father described the shift from celebrating the birth of their new baby to the receipt of the news of the postnatal diagnosis of Down syndrome:

It's like, one second you're sort of celebrating, and the next second you're holding each other wondering what to do. It was the moment where the celebration of the birth was taken away, and that was really the difference, between the first and the second child, is that

there was no more celebrating. It just ended, it ended right there and it was replaced with, "oh my God!"

A participant talked about the importance of being congratulated and what it meant to him when he was congratulated:

He was probably somebody who knew me well enough that he said the right thing, and congratulations. I think that's an important thing and people sometimes don't realize that this is the most important thing to say to a person who has a baby "congratulations." It [is] a weird thing not to say that to someone, and a couple of people do 'cause they're thinking of the "whoah geez...I'm sorry," first they should say, "Congratulations! Can I help you? How are things going" but that's a big word "congratulations."

Information, Resources, and Referrals

Fathers reported that receiving information, resources, and referrals to Down syndrome support groups and organizations, as well as meeting other parents, were all very important. Participants said that access to resources as well as a parent-to-parent connection could improve the quality of the postnatal experience. Access to information, resources, and referrals helped fathers to feel supported while creating a feeling of empowerment. The feelings of fear and anxiety were diminished when fathers had the opportunity to become agents of change in situations that often left them feeling overwhelmed, anxious, fearful, and vulnerable. It was important that fathers received information, resources, and referrals so they could start the process of learning about what they needed to do to improve the quality of their children's lives. Furthermore, fathers needed support so they could provide the specialized support that their children would need.

Information, resources, and referrals for Down syndrome support groups and organizations were not always offered during the postnatal period. Some fathers received resources and others did not. Some fathers didn't want resources or found resources on their own. Several fathers could not remember if they received resources because the entire postnatal experience was so overwhelming.

One participant discussed his experience with resources in this way: We had to ask for them, we had to find someone...I had gone that night after she was born. I picked up our son and came home and then went back up there to the library that they had there; and they had nothing on Down syndrome. And I didn't end up finding anything and you'd think in a hospital they'd have something, but they didn't...finally we talked to a lady [who] ended up going to a

different hospital across town to get us a book on Down syndrome. And that is pretty much all the information we got, except since then we've got dozens of books and everything else we've been looking through. But it wasn't, I don't know, they didn't seem nearly as prepared as you'd think a hospital would be. It is one of the biggest hospitals in the area; there are probably 50 babies born there a week. You'd think they'd have a little more experience with Down syndrome, but they didn't.

Another father talked about the problem of being overwhelmed with too much information all at once.

They gave us one of the biggest packages; it was too much info. We didn't open it...we didn't look at it. I don't think we knew what to do, to be honest. And, I think that we knew we would have loved someone to talk to but our request came in the form of ten pounds of paper, and half the stuff I didn't look at.

Participants discussed the significance of talking with another parent (preferably a father) who had a child with Down syndrome, during the early stages of the postnatal period. Some fathers were given referrals; some did not receive referrals; others waited a long time until they heard back from peers they had been referred to. One father who received a referral to meet with a family said, "...we're friends with them to this day...yeah, they've been a part of our lives." Participants who had another parent, guardian, or family member of a child with Down syndrome to talk to in these early stages expressed how much they needed the support at that time. They reported how it felt to meet with someone who could truly identify with what they were going through, because they "knew what this was."

Fathers' Emotions

Participants named a combination of emotions ranging from sad, angry, shocked, devastated, elated, excited, happy, confused, to feeling relieved, anxious, and fearful, upon receipt of the news. Fathers discussed the experience of navigating the realm of new learning about Down syndrome while integrating the implications and realities of the newborn's diagnosis. The implications of the newborn's diagnosis often came with added adversities, which often manifested as disability oppression perpetuated by medical personnel. Fathers recalled oppressive comments made by medical personnel or other members of the hospital community, comments they reportedly experienced as especially hurtful.

A father described how he felt and what he was thinking. He recalled the questions he had. His questions illustrated concerns about his fear of the unknown. He recalled:

I had a tough go...I always say that it took me 48 hours to recognize that I was probably thinking more about myself than the child that I needed to take care of. But that's how it was. I remember those initial hours in the hospital were very difficult for me. Of course, all the questions going on in your head, "What [is] this going to be like? What are we going to be facing? What are the challenges? What health issues are we going to have? At that point, all the things that go with the emotional and health-related challenges of having a child and then now being told that she has a disability and challenges [as well]. It definitely struck me in a difficult way.

Also, fathers reported that they felt that they needed to take care of everything when their child was born. Several fathers expressed that they felt they had to shut down their feelings so they could support their families. One father explained how it took him about a year before he talked about his feelings. Also, he poignantly described the shift from feeling very proud and happy to feelings of fear and anger:

My first son... I guess I was the typical father when my son came out. I was about as happy as I could be. I think it was the proudest moment of my life and just looking at him, seeing him look back at me and we were just staring at each other for a couple of minutes while they cleaned him off. He couldn't even look over at [his] mom. He just looked at me. I was shaking. I was crying. I was so elated, so happy. Initially they said he looked good and everything was fine. We were just proud parents and that lasted a good ten minutes. And then my world came crashing down. Basically, when they took him from the room and they told us they suspected that there was a possibility of him having some type of chromosomal disorder, possibly Down syndrome, of course. I and my wife, well more so I, I really didn't know anything about Down syndrome. My wife is a special education teacher so she knew what they were talking about. But I didn't know how to react.

Participants discussed their feelings of fear and what issues came up for them when their children were born. Some said that fear was the driving force behind their feelings of sadness, anxiety, and anger. The fear that fathers described was essentially the fear of the unknown. Fathers often felt a significant decrease in their feelings of fear when their questions regarding their fears of the unknown were answered. A participant explored feeling fearful about the variety of unknowns for his daughter. He explained:

I was thinking about the future and all these things. I think one of the interesting things about having a special needs child is after a while you realize it's not such a bad thing. We don't think as far ahead as I think some people think about their children. And, it's a different view of it. For what I can reflect on, I'm thinking about the baby and the fear of the unknown. And if anyone tells you differently I'd be surprised. We're sitting there going, "I don't know what's coming next and I don't even know where to begin." I think anger is a fair word, "Why me? Why am I getting this? Why are the cards being dealt to me this way?"

Another father recalled his feelings of fear and questions that came to mind when the doctor determined the diagnosis:

There was nothing at that exact moment that was real logical. It was just fear of the unknown. The immediate fear of, "oh, my goodness! I just had a child and now I will never...I'm never going to have a relationship with this child."

Another participant elaborated on feelings of fear that he felt after he learned of his son's diagnosis:

Fear of the unknown! Absolutely! Because you think as parents ok this is our second child. I already know what it is like to have a kid. But I don't know what it is like to raise a teenager yet. But we kind of get what it's like to have a kid, for the first couple of years. Those aren't mysteries to parents, but I think there was a feeling in this case that this is different. That this is going to be very different than my daughters. Fear about the unknown. What it is going to mean for us? What is it going to mean? And something we come back to is, we're not going to hide anything from our daughter and she understands she has Down syndrome and that she is different. But the question is, "what is going to happen after we die? Who is going to take care of us?" And we don't want our daughter to grow up thinking she has to be that person. So, again more of these fears and questions coming in, about bigger picture items and what is going to happen down the road.

Insensitive Comments

Some participants described their feelings regarding otherwise well-intended comments, which they often experienced as oppressive and insensitive. Insensitive comments often perpetuated stereotypes as well as feelings of pity, which may generate a feeling of shame for new fathers. Comments, such as what this father described, perpetuate stereotypes about people with Down syndrome. He explained:

There was a nurse there who made a comment. One of these slip comments, "these kind of kids, we love 'em." And we're not even close to thinking about it. [It was] so irresponsible and inappropriate and I remember getting in touch with the hospital administrator. I was so peaved. [It had] crossed the bounds. Nurses have jobs to do and she's just a nurse in that kind of room. My doctor was the one who should have the comments. While we [were] still trying to digest, and figure this out, I recall it was very inappropriate.

A father recounted a visit from a church volunteer while he was in the pediatric intensive care unit with his son. His son was recovering from open-heart surgery. He remembered:

[A woman who visited] was a member of one church, I don't remember what church but the thing is she was visiting the hospital, giving some kind of spiritual support to people there. So, at that moment I was with my son and she knocked at the door and she introduced herself and she tried to do her work. I didn't want that, but I tried to be nice to her. I explained what was my son's situation and she said, "oh yeah, I can see that in his face."

Fathers' Recommendations

Fathers suggested how things could have been improved during the postnatal experience while they were at the hospital. They were deeply affected by the disability oppression that they were confronted with, as manifested in the attitudes of medical personnel. At this time when fathers needed support, rarely did participants feel supported by medical personnel. Some fathers felt supported but most of them left the hospital wishing their experience could have been better. Overall, fathers felt strongly that hospitals should be more prepared and that medical personnel should have better training about delivering a postnatal diagnosis of Down syndrome.

One father described what the attending physician said, how he felt about what was said, and what he would have preferred to hear:

And our attending physician, who we didn't know, she just, I don't know, she just wasn't a good people person. She was just saying the wrong thing all the time. Like [she said], "I don't think this is a big deal. I've seen a lot of babies with Down syndrome." If she had to do it all over she would've come in and she would've said, "There are ten things that we look for. One thing, the heart sounds fine that doesn't mean anything, the eyes look a little small, the toes have a space between them [and] there is a little roll of fat in the neck." And then

just go through the whole thing and then she should've said, "This might sound terrible but it's not."

Another father explained how helpful having someone with first-hand knowledge of Down Syndrome--a parent, guardian or caregiver--would have been:

There is no way that the news could not have been devastating considering my experience or certain lack of experience and complete lack of knowledge about what Down syndrome actually is. The initial devastation would've been big and I've had very little contact with people with Down syndrome prior to this. I think I would pick somebody or basically a parent of somebody with Down syndrome or a parent or a grandparent would be ok, [they] would be the ideal person to deliver that news. Somebody who is essentially your peer in that situation...that would be huge because it's sort of like somebody you know who can literally relate to what you're going through.

One man talked about his recommendations to new fathers and to medical personnel:

I think that...you got to have somebody who can actually come to you and deliver, cause if you're talking to someone and you're "oh, do you have a Down syndrome child" and it's like "oh, that's great information," but they don't know, they don't really know, and that's why I think it is important to talk with someone who has a kid with Down syndrome. And all these other groups who [they] try to quickly connect you with...I can't say enough about within 24-48 hours connecting a parent who's open to doing it. And that's the challenge. Everybody is unique, and I think 48 hours 'cause it may for somebody else be a week later or two weeks later, but knowing that there is some group or somebody they can talk to and see that kids thrive, and to say that, "yes, you can have some challenges and who doesn't have kids without challenges...oh mine are just a little different."

Another participant wished that he and his wife had been told of the diagnosis when they were together.

We didn't really have time to ask the questions. She looked so well [that] her health wasn't a real concern...I would've wanted to know what our outlook should be for our daughter and how we needed to prepare. There was a lot of great early intervention [that] was really productive [and] her schooling was really productive. Once we got out of the hospital and connected with somebody, we were just on the fast track. I used to do a lot of just therapy work with my daughter and I was really into it and that was my job. So after that I felt really

well informed. But just the delivery was so harsh, it was so hard to get over, the hospital was just a really uncomfortable place to be.

He continued:

I would have liked for them to explain their concerns and their suspicions and if they had explained what their process would be going forward. Just in figuring things out for my daughter [and] reassuring us that they are going to take great care of our daughter. And get us information and give us some resources and tools to make sure that our daughter will live a productive life. That would've been nice.

Other Findings

Fathers interviewed for this study made additional comments that are important to include but are not necessarily relevant to their experiences of postnatal support.

Heart Surgery

Fathers whose children with Down syndrome were born with a heart condition reported a somewhat different process than fathers whose children were born without heart conditions. Fathers whose children did not have heart surgery often commented on their feelings of gratitude that their children did not have to deal with the surgery. Participants discussed the heart surgery as being a very challenging and frightening aspect of their children's births—yet, they often reported that the heart surgery was ultimately successful. Also, they often felt very supported by medical personnel through this process, more so than how they felt when they received the news of a postnatal diagnosis of Down syndrome in an unspecialized setting (i.e., labor and delivery.)

Superstars

A participant discussed what he termed "those superstars that we meet." When children with Down syndrome are born, parents are often informed about people with Down syndrome who are usually very high functioning and, in effect, meet the conventional societal definition of "successful." Medical staff may offer this information in an effort to give parents hope for their children in an ableist society.

Process

Some fathers articulated their feelings and experience with a great deal of ease, whereas several participants did not feel at ease when they reflected on their process and emotions. Often fathers had an easier time reflecting on feelings when they spoke about their perception of their partners' feelings. Many fathers expressed a deep gratitude and appreciation for participating in this study. Some participants said that it was very helpful for them to have a space to process their feelings. Eleven out of thirteen fathers cried during their interview at various points when they reflected on their child's birth. For some fathers, the interview was the first time since their child was born that they explored their feelings about their child's birth.

Discussion

The research with fathers yielded findings similar to Skotko's (2005a; 2005b) research with mothers. One of the differences between the two studies is that this project used interviews that gave more depth to the recounting of the fathers' experiences than the quantitative and qualitative survey instruments yielded in Skotko's (2005a; 2005b) research with mothers. The findings from this study, as well as the pre-existing research of Skotko (2005a; 2005b), revealed that both mothers and fathers infrequently received up-to-date and relevant information/resources and referrals to local support groups. Mothers and fathers expressed that it was very important and helpful to have access to up-to-date information and referrals upon receipt of the news of a postnatal diagnosis of Down syndrome.

Fathers in this study felt a range of emotions similar to those reported by mothers Skotko's (2005a) research. Those mothers reported feelings of shock, anger, and devastation that resulted in their feeling depressed, overwhelmed and anxious. One mother from Skotko's (2005a) study wrote, "Giving birth to a child with DS [Down syndrome] was very traumatic." Fathers reported similar sentiments as well as feelings of shock, anger, anxiety, and devastation. Another outcome was that the participants this study and Skotko's (2005a; 2005b) had many suggestions for improvements medical personnel could make.

Implications for People Working with Families whose Child Has Been Diagnosed at Birth with Down Syndrome

The following recommendations are based on comments of the fathers who participated in this study as well of mothers who participated in Skotko's (2005a; 2005b) studies

General recommendations.

- Staff, including physicians, should first congratulate the parents on the birth of their child.
- Hospital staff and pediatricians should be educated about Down Syndrome and community resources for families with a child with DS in advance of working with the issue.
- Medical staff should be ready to provide up-to-date information, resources, and referrals to local support groups. They should be thoughtful about how and when to provide various resources. A packet of information may be helpful, but should be accompanied by inquiring as to what the parent(s) feel they need.
- Medical staff and social workers should be aware of the range of coping styles of parents upon hearing the news that their child may need medical and other interventions. Some people want to know their options and how this will affect their lives early on. Others may feel numb, or conversely, may feel overcome with emotion and need someone to process with before they can begin to plan.

Physicians.

- Physicians should disseminate the diagnosis as soon as they suspect it.
- A physician whom the parents know should convey the diagnosis to the parents.
- Physicians should give the news with both parents present.
- The news should be delivered in a private setting.
- The newborn baby should be present.
- Physicians should be thoughtful, present, empathic, and sensitive regarding the language they choose when disclosing and explaining the diagnosis.
- The physician should refrain from prefacing the disclosure of the diagnosis with, "I'm sorry..."

- Physicians and medical personnel should refrain from sharing any insensitive, pitying, and shaming comments as well as any personal opinions.
- Although physicians should integrate positive aspects of Down syndrome when describing the diagnosis, they should refrain from making superstar comments. They should consider how they can present optimistic comments without pressuring the parents to be perfect.

Other hospital staff and other aspects of the hospital experience.

- Hospital staff should coordinate a connection with a parent volunteer within the first 24-48 hours of parents' receiving the diagnosis.
- Physicians, medical personnel, and social workers should check their biases before interacting with parents. If hospital staff needs more training, or their own psychotherapy, they should take responsibility for it and not project onto the parents they are working with.
- Physicians, medical personnel, and social workers should not perpetuate disability oppression as manifest in stereotypes about people with Down syndrome.

Disability Oppression

Disability oppression and its manifestations in the attitudinal beliefs of medical personnel was a pervasive experience for many fathers. Many participants felt oppressed and stigmatized by the postnatal hospital experience. Fathers expressed feeling more relaxed and at ease after returning home from the hospital. They felt it didn't take long before they were accepting their children's diagnoses and felt ready to move forward to learn about the resources and supports they would need to support their children. A contributing factor to their feeling better at home appeared to be that they were not interfacing with the effects of disability oppression because they were no longer at the hospital. Inevitably they dealt with oppression in many other arenas and, sadly, will continue to do so, but at least in these early stages, fathers identified home as a kind of necessary respite from the hospital experience.

Institutions, such as hospitals and schools, perpetuate disability oppression through the attitudes that inform policy and policies that

inform staff's attitudes. Hospitals and schools embody and perpetuate these paradigms of oppression as microcosms of the larger society. These oppressive attitudes and beliefs perpetuate stigma. In effect new parents are being stigmatized and traumatized by comments made with almost every birth of a child with Down syndrome. This trend is a direct result of the effects of unexamined attitudinal beliefs about disability that are often embodied by many people working in the medical profession.

Doctors, medical personnel, and social workers need specialized training about delivering a postnatal diagnosis of Down syndrome. The Prenatally and Postnatally Diagnosed Condition Awareness Act was passed in 2008. The bill suggested that medical providers:

- (1) Increase patient referrals to providers of key support services for women who have received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;
- (2) Strengthen existing networks of support through the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other patient and provider outreach programs; and
- (3) Ensure that patients receive up-to-date, evidence-based, information about the accuracy of the test. (S. 1810, 2008)

Although this bill was passed six years ago, a great need still exists for the suggestions of this act to be implemented within the labor and delivery unit in each and every hospital across the United States. Quality support for parents upon the receipt of a postnatal diagnosis of Down syndrome should not be limited to a few hospitals in only a handful of cities in a couple of states. Quality postnatal support should be available to *all* parents, as the Senate bill implies. Our hope is that parents will feel supported and empowered during the postnatal experience as a result of the thorough implementation of the Prenatally and Postnatally Diagnosed Condition Awareness Act.

Limitations of the Study and Ideas for Further Research

The sample size of 13 participants was a limitation for this pilot study. The small sample size did not yield as much data as a larger sample might have. Despite the small sample size, important

information came to light as a result of the interviews with these few fathers. Also, even though the study was mostly limited to one geographical region, an unexpected finding revealed striking differences in the quality of services amongst hospitals in eastern Massachusetts compared to hospitals in western Massachusetts.

Another limitation was the lack of diversity in this sample because the majority of research participants learned of this study through an organization for people with Down syndrome and their families. Often members of Down syndrome organizations tend to be people who have more resources and support systems to negotiate their situations than some others. Most participants were white, middle class, married, middle aged, and employed. As a result they had Internet access as well as adequate time for participating in such organizations. These organizations tend to cater to white middle class people, thus contributing further to the lack of diversity in this sample. Another contributing factor to the lack of diversity in this sample is that the research could only interview people who spoke English. A study exploring the experience of fathers of color and the intersections of racism and disability oppression upon the receipt of the news of a postnatal diagnosis of Down syndrome would address the limitations created by the of lack of diversity in this study.

A larger scale qualitative and/or quantitative study for fathers dealing a postnatal diagnosis of Down syndrome, similar to Skotko's (2005a; 2005b) research with mothers, would make a greater contribution to pre-existing literature on the topic of fathers and postnatal support than this smaller scale study. Also, a study exploring the experience of fathers and the impact of internalized messages regarding gender roles as well as a father's sense of identity upon the birth of a child with a disability would be another important contribution to social work and postnatal research.

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