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Desiree D. Lowit
The Experience of Fathers upon the
Receipt of the News That Their
Newborn Babies Had Been Given a
Diagnosis of Down Syndrome: An
Exploratory Study

ABSTRACT

This exploratory study was undertaken to investigate the experience of fathers upon the receipt of the news that their newborn baby had been given a diagnosis of Down syndrome. Skotko's (2005a, b) study revealed that mothers of children with Down syndrome had predominantly negative postnatal experiences. Mothers reported feeling anxious, frightened, guilty, angry, and in a few cases suicidal.

I gathered information from interviews with 13 fathers. Interview questions were designed to explore the fathers' experiences of postnatal support. The criteria for the study involved that the participants must have a biological child who was born with Down syndrome in the United States in the last 15 years. Additionally the father must have interacted with the western medical community regarding their child's birth.

The major findings of this study revealed that fathers often experienced the messengers of the news of a postnatal diagnosis of Down syndrome as insensitive and pessimistic. Fathers often reported that they received the news of the diagnosis separate from their wife or partner. Participants frequently explained that they were not congratulated for the birth of their child. In many cases fathers recalled that the diagnosis was not disclosed by their obstetrician. And fathers reported that they were usually notified of the diagnosis without the presence of their newborn.

Findings for this study implicate that a larger scale and multi-culturally diverse study is

necessary. Overall, fathers felt strongly that hospitals should be more prepared, and that medical personnel should have better training for delivering a postnatal diagnosis of Down syndrome.

THE EXPERIENCE OF FATHERS UPON THE RECEIPT OF THE NEWS THAT THEIR
NEWBORN BABIES HAD BEEN GIVEN A DIAGNOSIS OF DOWN SYNDROME:
AN EXPLORATORY STUDY

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

Desiree D. Lowit

Smith College School for Social Work
Northampton, Massachusetts 01063

2010

Acknowledgements

I dedicate this thesis to my beloved son, Ulysses. Thank you. If it were not for your remarkable entry into my life there is so much in the way of love and compassion that I would have never accessed. You are my greatest teacher. I love you. Thank you for showing me the way.

I would like to thank my mother, my father and my grandmother for all their encouragement. Thank you Mary T. for your friendship and wisdom as well as all that wonderful laughter! Thank you Michael Dunning, my partner, my love, for all your nurture and support and for helping me to pick up, and move forward to bring my thesis to completion. Thank you, Mary Beth Averill, my thesis advisor, for your incredible dedication, patience and faith in my ability to finish this project.

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CHAPTER I

INTRODUCTION

This exploratory study examined the experience of fathers upon the receipt of the news that their newborn baby had been given a diagnosis of Down syndrome, using information gathered from interviews with 13 fathers.

One in every 733 babies is born with Down syndrome. Down syndrome occurs at conception. Down syndrome is determined when an individual is born with 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. There are more than 400,000 people who have been given a diagnosis/label of Down syndrome living in the United States (National Down Syndrome Society, n.d., ¶ 1).

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 will 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 initial reactions, and whether or not resources were shared.

It is important that parents receive the news of a diagnosis of Down syndrome in an empathic manner without the possible bias of the messenger. Parents would like to receive the postnatal diagnosis of Down syndrome with a sense of optimism and possibility for their

newborn. They would also like to receive up-to-date information about Down syndrome as well as access to referrals, supports and other resources regarding any other necessary services (i.e., early intervention services).

Previous research (Skotko, 2005a,b) has been done on the experience of mothers upon the receipt of the news that their newborn baby has been given a diagnosis of Down syndrome. Skotko (personal communication, 6, July, 2007) suggested that similar research is needed as it relates to the experience of fathers'.

Skotko's study (2005a) was the most salient literature in the research thus far. In Skotko's (2005a) study, mothers of children with Down syndrome in Spain completed a survey about the postnatal support services they received immediately following the diagnosis of their child. Mothers reported feeling anxious, frightened, guilty, angry, and in rare cases suicidal. According to most mothers, physicians did not give adequate amounts of information about Down syndrome and rarely did physicians give enough them printed materials or make referrals to parent support groups. Skotko's (2005a) included recommendations on how the medical system could be improved in Spain with implications for other countries including the United States.

Generally most physicians find that the experience of relaying the news of a postnatal diagnosis of Down syndrome is not simple. "Even the most seasoned physicians admit that they have little, if any, training on how to discuss a new diagnosis of DS [Down syndrome] in a sensitive manner. In a survey of 2500 medical school deans, students, and residency directors, 81% of medical students report that they 'are not getting any clinical training regarding individuals with intellectual disabilities,' and 58% of medical school deans say such training is not a high priority" (Skotko, 2009, p. 854).

This study may be especially helpful to social workers working in hospitals, early intervention programs and schools; generally this project may be useful to all social workers in all settings. This research may work in the service of diminishing stigma and stereotypes about parents who have children with disabilities. It may help to diminish the spread and impact of attitudinal beliefs about people with Down syndrome and their families, attitudinal barriers and beliefs that are often perpetuated by medical professionals and social workers.

This project may help parents so that they feel more empowered and will become more effective advocates for their children as a result, thus improving the quality of life for people with Down syndrome and their families.

Also, the findings from this study could be a useful contribution in terms of generating more awareness and support around the needs of fathers upon the receipt of the news that their newborn baby has been given a diagnosis of Down syndrome. The hope is that this study will help to diminish feelings of anxiety, isolation, guilt, fear, and anger that fathers of children with Down syndrome might experience during postnatal support.

CHAPTER II

LITERATURE REVIEW

This chapter will examine pre-existing literature as it relates to parent perspectives and experiences, Down syndrome facts and statistics, a brief history of institutionalization and its legacy, medical perspectives, and empowerment.

Parent Experiences and Perspectives

With the exception of a few studies done in recent years overall there has not been much done in the way of research on parent experiences and a postnatal diagnosis of Down syndrome. Studies that have been done thus far have been primarily focused on mothers. Skotko (2005a, b) completed two quantitative and qualitative studies. The first study (2005a) involved the distribution of an 11-page survey that was mailed to 6,125 mothers in Spain. Using the same methodology, Skotko (2005b) surveyed 2,945 mothers in the United States. These two studies both completed 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 they felt during and then days following the birth, implications for improvement, etc. He intended to collect data that could be used to improve protocol in hospitals of how the news of a diagnosis of Down syndrome is delivered to mothers.

Skotko's (2005a) 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 U.S. 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.

Skotko (2005a) developed a list of recommendations to physicians on how to effectively/empathically deliver the news based on his research findings. These suggestions were compiled with data from the research participants. The suggestions are as follows:

1.) The person delivering the news should be a physician. 2.) The physician should deliver the news with both parents in the room, whenever possible. 3.) The physician should deliver the news in a private setting. 4.) The physician should convey the diagnosis as soon as she/he suspects it. 5.) The physician should use sensitive language. 6.) The physician should include positive aspects of Down syndrome when explaining the diagnosis. 7.) The physician should not share his/her personal opinion. 8.) Parents should be provided with up-to-date printed material. 9.) The physician should offer the contact information of a local support group. (p. 241)

Skotko (2005a, b, c) very successfully met the purpose of the study in that the findings of his three research articles (Skotko, 2005a, 2005b, 2005c) worked in the service of the creation of Senate bill, S. 1810, The Prenatally and Postnatally Diagnosed Condition Awareness Act. This bill was passed as a result of Skotko's testimony prepared for the Down Syndrome Congressional Caucus on February 26th, 2009. 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 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)

The implications of Skotko's (2005a, b, c) research focused primarily on mothers. In fact, the Senate bill is geared toward improving the experience of prenatal and postnatal support for mothers. Previous research on the experience of postnatal support has been focused on

parents/families without specific focus on mothers or fathers.

Skotko's (2005a, b) study was limited in that it was restricted to mothers and it was not a socioculturally diverse sample in that the majority of participants were white, Catholic and educated. Positive aspects of the study include that it was the largest scale study known to date on the topic of mothers of children with Down syndrome and postnatal support. 9,070 research participants were surveyed for this study. It was an international study.

A research project focused on the general experience of fathers of children with Down syndrome was started, yet not completed, by Graham (n.d.). Graham (n. d.) offered a one-page bullet point description of the research findings. Graham (personal communication) explained that she collected much in the way of data with fathers yet she did not use the data for anything beyond the one page bullet point description of her findings. Father's concerns or/and comments from Graham's findings revealed that father's experienced medical professionals to be generally negative and cold when delivering the diagnosis. One father from Graham's study said, "The Dr. delivered the news like a bull in a China closet." Also, fathers expressed a need for more "father only" support groups.

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 have been born within the last 15 years. He 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, 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 hours, as the nurses worked on James, and Janet and I tried to collect my 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?

Berube (1996, p. 6) later reflected:

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? Christ, we'd only just finished paying off the bills for Nick's birth two months earlier, and now were going to plunge into the kind of catastrophic medical debt that only American health care can make possible? These were selfish thoughts and the understanding that selfish thoughts might be "natural" at such a time didn't make them any less bitter or insistent.

Berube's 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.

The following accounts are from mothers. The research for this portion of the literature review resulted in an extensive collection of accounts by mothers. The mothers cited here reflected on their experience of postnatal support. The mothers reflected on the words that were spoken and how they felt upon the receipt of the news that their newborn baby had been given a diagnosis of Down syndrome.

Rimmer (2007) reflected on her experience of her daughter's birth: "Finally, the NICU doctor came to see us. 'She has a heart defect,' he explained, 'and she has Down syndrome. We have to fly her to Labonheur Children's Hospital immediately.'" Rimmer expressed how she felt:

What was supposed to be one of the best nights of our life turned into complete hell. I cried all night, thinking I would never hold my daughter, or even get to see her. I prayed until morning, and didn't sleep at all. Shane stayed with Alexis all night. I felt so empty without her. I felt it was all my fault. (p. 45)

Pollard (2007) described how she felt after the receipt of the news:

During those first hours following the diagnosis, I was full of fear of the unknown. I was angry, sad, hurt, and felt lots of self-pity. Then of course, I wondered how this would affect my other children and how they would react to their new brother. (p. 48)

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 Bollinger 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 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)

Down Syndrome Facts and Statistics

This section gives a detailed overview of some basic information about Down syndrome as well as definitions of what Down syndrome is and how and when it occurs. This section also provides medical information about various health issues a person with Down syndrome could be at higher risk for.

The National Down Syndrome Society (NDSS) website (n.d.) provided up to date and thorough information about Down syndrome such as potential health issues, implications for

adulthood and independence, strengths, possibilities, and other research:

Down syndrome occurs at conception. It occurs when an individual is born with three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development for a child and is the cause of the characteristics that are associated with Down syndrome.

Down syndrome is the most common to occur of chromosomal conditions. One in every 733 babies is born with Down syndrome. There are more than 400,000 people who have been given a diagnosis/label of Down syndrome living in the United States. Down syndrome occurs in people of all races and economic levels.

The incidence of births of children with Down syndrome increases with the age of the mother. Yet due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.

People with Down syndrome have an increased likelihood for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.

A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.

Life expectancy for people with Down syndrome has increased dramatically in recent decades - from 25 in 1983 to 60 today. People with Down syndrome attend school, work, participate in decisions that affect them, and contribute to society in many wonderful ways.

All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.

Access to quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.

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)

History of Institutionalization and Its Legacy

A brief overview of the history of intellectual disability and its relationship to the medical institution, religiosity and capitalism is an important link to understanding the origins of the legacy of attitudinal beliefs that often inform the views of medical workers today. Attitudinal beliefs perpetuate stigma, such as the stigma that parents reportedly confront when their child with is born with Down syndrome.

J.L Down, after whom the syndrome is named, was head of the Earlswood Asylum in Surrey, England from 1858 to 1868. Down was a prosperous young physician at the time of his assignment. He continued his research at the Earlswood Asylum as he observed and cared for hundreds of children during his tenure (Wright, 1996). “In 1866 he published a paper that was also included in his *Mental Afflictions of Children and Youth* (1887), describing today what is known as the Down syndrome phenotype”(Yong, 2007, p. 49).

At that time Down presented a new evolutionary hypothesis, which was informed by social Darwinism as well as racism. Borsay (2005) explained:

Down believed that certain children he observed and cared for in the asylum, children who shared specific traits, were “Mongoloids,” a product of the spontaneous reversion by caucasian children to an earlier, “less developed” race. (p. 101)

Yet by the late 1870s’ Down had discarded this hypothesis because he was opposed to slavery and the anti-abolitionist arguments (Ward, 1998).

Wright (2001) explained that despite Down’s rejection of this hypothesis regarding “Mongoloidism,” the term continued to be used by the medical profession:

However as theories of racial degeneration were circulating in Europe, Great Britain and North America, in the mid-nineteenth century, “mongolism” stuck and served to inform the ethnic/racial hypothesis for ‘idiocy’ well into the twentieth century. (p. 156)

Down was considered, by his medical colleagues to be a pioneering researcher for his time. He

believed that people with intellectual disabilities could be educated and even “cured.”

Without the resources, societal structures, support and research to strengthen and integrate the otherwise progressive ideas of Down, the asylums became over-populated with people with cognitive, developmental, intellectual and physical disabilities who continued to be under served. Yong (2007) explained:

By the end of the nineteenth century, however, the euphoria over the pioneering research of individuals like Seguin and Down had abated. The initial optimism that all children with intellectual disabilities could be educated and even cured had disappeared as a growing number of “unteachable idiots” populated the asylums. But as institutions expanded their services to accommodate and deploy the feebleminded within their walls, the demand for physicians like Down and their staff also increased. (pp. 49-50)

Ferguson (1994) described the effects of these changes:

Major developments in the area of mental retardation in the last half of the nineteenth century was not the triumph of custodialism but its medicalization... This, in turn, was intimately associated with the rise of a new professional class of institutional experts, and its quest for respectability as a medical specialty. (p. 160)

The beginning of the 1900s was a time marked with delinquency, deviancy, prostitution, alcoholism and pauperism. Blame for these societal problems was continually shifted to the “feebleminded” (Yong, 2007, p. 50). Yong (2007) elaborated on the belief systems of this era:

The emerging challenge of moral imbecility would prove to be as intractable as mental imbecility. If moral imbeciles could not be deterred by punishment (since they lacked the kind of abstract thinking that could make connections, follow out consequences of their actions, or learn from past mistakes), then asylums needed to develop alternative means of social control. The medicalization of the feebleminded would soon turn in increasingly ominous directions with the development of “scientifically legitimated programs” of intelligence testing, sterilization, and eugenics designed to deal with the problems of imbecility. (p. 50)

Institutionalization and the practice of eugenics are now seen as “abuses of power in the name of science and social necessity” (Smith, 2003, p. 58). This is seen today not only in contemporary practices surrounding prenatal testing but also in the debates surrounding euthanasia. Although this topic is broad it is important to note that people with “intellectual

disabilities were at the mercy of ‘experts’ (physicians, psychologists, scientists, etc...) as long as they were institutionally confined” (Yong, 2007, p. 54).

America is a capitalist society and disability is strongly linked with an ability to work and be productive. This creates a close identification of disability and employability (Albrecht, 1992). America as a society values independence, physical strength, and freedom, all values that people with disabilities may also value but may not be able to fulfill in the same way as people without disabilities. The values of a society inform the beliefs of the individuals in the given society. Capitalist values inform the attitudinal beliefs of individuals today in a ‘doing’ culture.

Charlton (1998) wrote about the paradox of disability and capital:

A fundamental paradox confronting the disability rights movement is that the progress of people with disabilities is contingent on significant economic development (the accumulation and expansion of capital) and, correspondingly, the emergence of (more) modern ideas about disability (the influence of capital) and, at the same time, the development of a movement that insists on social justice and equality (the restriction of capital) and an epistemological break with the dominant ideology (the rejection of capital). (p. 154)

Medical Professional Perspective

The perspectives of medical professionals will be explored in this section with a general overview of ideas and attitudes that historically and currently often inform how physicians inform parents of a diagnosis of Down syndrome. This literature includes the medical model of disability, prenatal testing and disability rights. The focus of this section is to illustrate how attitudes and lack of adequate training inform perspectives that often perpetuate disability stigma and oppression for new parents and their children with Down syndrome.

The Medical Model of Disability

The medical model of disability informs medical professionals’ current attitudes about disability. 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 disabled people 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)

Ralston (2000) wrote about what he had learned through trial and error as a physician in the realm of the quality and impact of patient relatedness. An important experience with an expectant parent was a great lesson to Ralston as it related to conveying the news to patients of a possible prenatal diagnosis of an unknown fetal abnormality:

This experience made it obvious to me that it is not only important to present the information clearly and in language and terms that patients can understand, it is just as vital to listen to patients to know what their assessment of the risks might be. The language we use in talking to patients is so crucial, and yet so unpredictable in its impact. (p. 338)

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 of individual models and societal models (Figure 1). Although there are multiple models, 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 integrate issues of oppression and diversity. The medical model as an individual model reinforces or/and perpetuates the problems of stigma and disability oppression.

The following selection from a report made to the legislature of Massachusetts in 1848 by Samuel G. Howe offers insight into the attitudes as well as their manifestation as in the individual models of disability that informed decisions made in legislation. The legacy and its impact, although not as macro-aggressive as the beliefs of 1848, still manifest today. The report was written as an inquiry regarding “the condition of the idiots of the Commonwealth, to

ascertain their number, and whether anything can be done in their behalf” (Howe, 1972, p. xi-xii):

It is recommended that measures be at once taken to rescue this most unfortunate class from the dreadful degradation in which they now grovel. The reasons for this are now manifold, and hardly need to be repeated. In the first place, it would be an economical measure. This class of persons is always a burden to the public. It is true, that the load is equally divided; it falls partly upon the treasury of different towns, and partly upon the individuals; so that the weight is not sensibly felt; but still it is not a whit the less heavy for that. There are at least a thousand persons of this class who not only contribute nothing to the common stock, but who are dead weights upon the material prosperity of the state. But this is not all; they are even worse than useless; they generally require a good deal of watching to prevent their doing mischief, and they occupy considerable part of the time of more industrious and valuable persons... The moral evils resulting from the existence of a thousand and more of such persons in the community are still greater than the physical ones. The spectacle of human beings reduced to a state of brutishness, and given up to the indulgences of animal appetites and passions, is not only painful, but demoralizing in the last degree. What virtuous parent could endure the thought of a beloved child living within the influence of an idiotic man or woman who knows none of the laws of conscience and morality, and none of the requirements of decency? Every such person is like a Upas tree, that poisons the whole moral atmosphere about them. (Howe, 1972, p. xi-xii)

The societal models validate the notion that the only problem with disability is other people’s attitudes. This notion resonates deeply for people living with disabilities in a society with attitudinal barriers, with which parents often interface upon the receipt of the news that their newborn baby has been given a diagnosis of Down syndrome.

Beliefs and attitudes about disability are individually experienced but socially constituted. They are, with few exceptions, pejorative. They are paternalistic and often sadistic and hypocritical. When blatantly pejorative attitudes are not held, people with disabilities often experience a paradoxical set of “sympathetic” notions like the courageous or noble individual. Attitudes such as “I couldn’t adjust to such a life, he must be so strong” or “She has overcome so much to be successful” derive from and feed the same beliefs as pity, contempt, or shame. That is, if a person with a disability is “successful” or seems to have a good life, he or she is seen as brave and courageous or special or brilliant. Given the intrinsic abnormality or awfulness of disability, anyone living a normal or ordinary life must be extraordinary. (Charlton, 1998, p. 52)

Peters and Castaneda (2000) defined disability oppression theory as integral to the more

general definition of the societal model:

First disability oppression theory describes the pervasive and systemic nature of discrimination toward people with disabilities referred to as ableism. Second, this theory identifies the process by which people with disabilities journey toward empowerment and liberation through the establishment of equitable access to and accommodation within society's systems, and through the creation of an interdependent social structure in which all persons are connected and depend on each other to perform equally important community roles. (p. 320)

Prenatal Testing

Disability is a social construct that impacts one's quality of life often before one is even born. Prenatal testing has become an area of great debate as selective abortion continues to decrease the number of people coming into the world who would have been born with a diagnosis of Down syndrome.

Sociologist Kitty Felker interviewed twenty mothers of children with Down syndrome. These mothers reported that before their babies were born, "clinicians had stressed the horrors of life with disabilities," while their families themselves described instead the satisfactions of parenting children with disabilities. (Saxton, 2000, p. 158)

Saxton (2000, p. 158) questioned, "If a condition (like Down syndrome) is clearly unacceptable, how long before the line moves toward other (presumed genetic) characteristics fraught with a social charge: sexual orientation, race, attractiveness, height and intelligence?" Selective abortion calls for an exploration into the larger issue of quality control of all humans. Selective abortion and prenatal testing are practices that are informed by three of the individual theoretical models (defined earlier) of disability: the medical, eugenics and social Darwinist models.

	Individual Model	Societal Model
Definition of Model	<p>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 changed for the general good of society (Rothman 2003, p. 4).</p>	<p>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).</p>
Example Models	<p>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).</p>	<p>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).</p>
	<p>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).</p>	<p>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).</p>
	<p>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</p>	<p>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,</p>

	Individual Model	Societal Model
	own survival, people who were unable to survive on their own due to disability could be left to their fate (Rothman, 2003, p.7).	pp.30-31).
	The Eugenics Model -Supporter’s of eugenics took Darwin’s position even further. If only the fit should survive, the eugeniscists said, then not only should we abandon those who are “unfit,” we should also isolate them from the rest of society 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).	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 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).	

Figure 1. Individual and societal models of disability

According to Saxton (2000), prenatal testing was developed with the intention of identifying high risk pregnancies and has become a part of routine prenatal care. Yet, these tests and the prospect of selective abortion raise many social and ethical concerns. Disability rights activists believe that prenatal testing and selective abortion are morally problematic. Members of

the disability rights community hold the perspective that selective abortion might be based on the assumption that “any child with a disability would necessarily be a burden to the family and to society, and therefore would be better off not being born” (Saxton, 2000, p. 147).

According to the disability rights community, “if suffering does indeed attend life with disability, then the place to begin ameliorating that suffering is with the eradication of social discrimination—not with the eradication of people with disabilities.” (Saxton, 2000, pp. 147-148)

Disability Rights

This section briefly describes the disability rights critique of pre-natal testing. This section also includes a brief exploration of what messages a person with a disability might internalize regarding issues of selective abortion and disability rights.

Although the movement has no one position on prenatal diagnosis, many adherents of the disability rights movement believe that public support for prenatal diagnosis and abortion based on disability contravenes the movement’s basic philosophy and goals. (Asch & Parens, 2000a, p. 4)

Most people with disabilities have the task of realizing that their disability is not the defining factor of their lives that oppressive societal assumptions indicate.

Your disability is a part of you, but really not that big a deal in the totality of your being. And now we learn from genetic science that the particular characteristics, “the flawed part,” that we fought against negative and learned stereotypes to accept, has now become the very factor identified by a technology as the excuse to eliminate potential people who might turn out “like you.” (Saxton, 2000, pp. 160-161)

People with disabilities fought hard against the negative beliefs, attitudinal barriers and learned stereotypes to accept themselves for who they are (Saxton, 2000). The impact of prenatal testing and selective abortion is detrimental to an already fledgling sense of the collective feeling of self-worth for many people living with a disability in this society.

The disability rights critique of prenatal diagnosis and selective abortion advances three claims. According to Asch and Parens (2000a), critics contended that:

- (1) Continuing, persistent, and pervasive discrimination constitutes the major problem of having a disability for people themselves and for their families and communities. Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.
- (2) In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion.
- (3) When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing, namely, "to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world and make us proud." (p. 13)

Empowerment

This section explores the stigma perpetuated by the medical model at a child's birth. The influence of the societal and empowerment models of disability will also be explored. This section examines the importance of sharing updated and relevant information, resources and referrals for support groups to parents. The perspectives of individuals who've been given a label of Down syndrome will also be included in this portion.

The most important thing that happens when a child with disabilities is born is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents. (Ferguson, Gartner & Lipsky, 2000, p. 74)

The following recommendation from Skotko's (2005a) research supports Asch's (2000) sentiments. Skotko's recommendation is from a list developed for physicians from the suggestions by research participants as a resource for relaying a postnatal diagnosis of Down syndrome:

The physician should use sensitive language. The tone of the conversation is frequently established by the first words used by the physician. Instead of saying “I’m sorry” or “I have some bad news to share,” physicians should first congratulate parents on the birth of their child. Mothers emphasized that having a child with DS is not a tragedy and should not be introduced as one. Also, the “M word”[mongoloid] is wholly derogatory and no longer deserves a place in medical nomenclature. (p. 241)

The medical model of disability manifests as parents continue to confront disability oppression when the news of a diagnosis of Down syndrome is received. Many parents report not having the opportunity to celebrate their child’s birth as they are instantly met with the attitude and disability oppression masked as medical concern for the development of their child. Skotko (2009) explained:

Research has shown that mothers forever remember the first words that their physicians use. They expressed the most satisfaction when their physicians offered congratulations over the fact that they had just had an infant. Parents further indicated a desire to be told the news with both partners and the infant present, whenever feasible. They also request sufficient time to receive a thorough explanation, with the opportunity to have all of their questions answered. At the end of the initial discussion, a follow-up appointment should be arranged within several weeks. (p. 755)

As important as relaying the news of a diagnosis as well as any possible medical complications is, of equal, if not utmost, importance is that parents are treated with the same respect that any parent would expect at the birth of any child. Ferguson, Gartner and Lipsky (2000) explained:

However, when we look at the history of professional responses to the birth of such a child, we find patterns of research and practice that have, until recently, assumed that the disability itself inevitably overwhelmed all other considerations. Whether seen as the cause or the outcome of the disability itself, the unfortunate family circumstances supposedly associated with such births were consistently presented as inherent and immutable. (p. 75)

The societal model of disability sets the stage for the empowerment model for individuals with disabilities. The empowerment model has been adapted for communities and families as

well as individuals. Rothman (2003) defined the empowerment model for communities (with implications for individuals and families):

The empowerment model for communities is an extension of the empowerment model for individuals and is built upon the same foundations: that human dignity and respect are an essential part of optimal functioning, and that oppression, exclusion, and discrimination undermine self-esteem. On this broader level, empowerment focuses on supporting a feeling of group [or individual] competence, connectedness, and the group's ability to effect change for good of all the members of the group. The skills, abilities, and personal characteristics of each member of the group are used together to promote and achieve the mutually determined goals... All members of empowerment groups have a stake in the resolution of problems. Thus empowerment group members may be family members, individuals in a support network of a person affected by the problem, or people with a special interest in the member's concerns. (p. 227)

Empowerment influences the societal model's focus of changing societal structures and attitudes to make the physical and social environments accessible to all individuals with disabilities so they can lead an independent existence.

Skotko's (2005a, b, c) research placed emphasis on the importance of parents' experiencing a feeling of empowerment with the information resources and referrals necessary upon the receipt of either a prenatal or postnatal diagnosis of Down syndrome. Updated information and resources are important so families can make informed and updated decisions and start the process of coordinating the provision of the services and supports that their child will need. Skotko's (2009) research suggested:

Physicians should provide parents with accurate information that emphasizes in very practical terms, what DS [Down syndrome] is, what causes the condition, and what it means to live with DS in today's society. As part of this explanation, physicians should hand parents an up-to-date bibliography list of DS resources, such as the reference lists available from the National Down Syndrome Society (www.ndss.org) or the National Down Syndrome Congress (www.ndscenter.org). (pp. 755-756)

Skotko's (2009) recommendations to physicians were based on the suggestions of research participants. The suggestions made by participants work in the service of dismantling stereotypes

and attitudinal beliefs about Down syndrome or disability overall by including essential components of the empowerment model:

Physicians should begin their conversations with positive words, such as congratulating the parents on the birth of their child. They should avoid language conveying pity, personal tragedy, or extreme sorrow; moreover, they should avoid offering unsolicited personal opinions. The first few words that doctors use have been shown to set the tone for the remainder of the conversation. Moreover, mothers remember the first words 20 years after the initial discussion. (p. 755)

The significance of sharing information, resources and referral at the child's birth is also important as an illustration of empowerment as an essential aspect of the disability rights movement. Charlton (1998) explained:

Historically, the only choice people with disabilities had in their personal struggle to survive was to individually resist isolation, even death, by relying on others. This meant, practically speaking, begging and becoming dependents of families or charities. That has begun to change. Now there is a movement of empowered people that seeks control of these necessities for themselves and their community. But this movement faces enormous challenges and choices as well. How these challenges are confronted will inform the effectiveness of the movement itself and its impact on the everyday lives of people with disabilities. These choices have life and death consequences. (p. 165)

Beyond Skotko's (2005a, b, c) research, I was not able to locate recommendations or approaches on how to effectively provide counseling to parents receiving a postnatal diagnosis of Down syndrome. However, I did locate information for counseling parents for a prenatal diagnosis of a disability. Although this information is more general and not specific to Down syndrome, it addresses different issues and considerations with some relevant overlap as Biesacker and Hamby (2000) illustrated:

The most extensive model, *the psycho-educational model*, includes offering information on the conditions under study but also explores thoughts and feelings that the information elicits in the client. It is collaborative; the counselor asks what information is most useful to the client in making a decision about prenatal testing. The client's experience with people who are affected with a variety of different types of disability may be explored in conjunction with her expectations for her own family. Working within this model, the counselor attempts to achieve an empathic understanding of the client's values as they

relate to having a baby, terminating pregnancy, and establishing a family. This model of counseling requires a great deal of skill and flexibility on behalf of the counselor. (p. 344)

It is often the case that people with disabilities are spoken for which is a part of the paternalism and disability oppression which Charlton (1998) referred to in the medical perspective of this thesis as well as an issue that Rothman (2003) addressed in her definition of the empowerment model which is included in the empowerment section of this thesis.

Kingsley and Levitz's (1994) expression of what Jason Kingsley would say to the obstetrician who tended his birth in 1974 is the most poignant piece of research for this literature review I've come across to date. Fortunately due to the de-institutionalization movement, this suggestion by doctors is no longer an issue, as it was when Jason Kingsley was born. Jason Kingsley is an author and self-advocate who was given a diagnosis of Down syndrome when he was born. Doctors today would no longer recommend institutionalization yet much of what Jason Kingsley relays from his parents' experience and his own sentiments is still relevant to issues that families and people with Down syndrome are currently dealing with. Kingsley (Kingsley & Levitz, 1994) commented:

When I was born, the obstetrician said that I cannot learn, never see my mom and dad and never learn anything and send me to an institution. Which I think it was wrong. Today we were talking about if I could see my obstetrician and talk to him, here are the things I would say... I would say, "People with disabilities *can learn!*" Then I would tell the obstetrician how smart I am. Like learning new languages, going to other foreign nations, going to teen groups and teen parties, going to cast parties, becoming independent, being... a lighting board operator, an actor, the backstage crew. I would talk about history, math, English, algebra, business math, global studies. One thing I forgot to tell the obstetrician is I plan to get a academic diploma when I pass my RCTs... I performed in "The Fall Guy" and even I wrote this book! He never imagined how I could write a book! I will send him a copy...so he'll know. I will tell him that I play the violin, that I make relationships with other people, I make oil paintings, I play the piano, I can sing, I am competing in sports, in the drama group, that I have many friends and I have a full life. So I want the obstetrician will never say to any parent to have a baby with a disability anymore. If you send a baby with a disability to an institution, the baby will miss all the opportunities to grow and learn...and also to receive a diploma. The baby

will miss relationships and love and independent living skills. Give a baby with a disability a chance to grow a full life. To experience a half-full glass instead of the half-empty glass. And think of your abilities not your disability. I am glad that we didn't listen to the obstetrician... We will send a copy of this book to [him] and say, "See page 27." I wonder what he will say. I wonder if he will come to us and call us and what is his response, and we hope he would say that he made a mistake. His emotional feelings is...sorry, depressed, and mistaken...He will never discriminate with people with disabilities again. And then he will be a better doctor. (pp. 27-28)

CHAPTER III

METHODOLOGY

This exploratory study researched the experience of fathers upon the receipt of the news that their newborn baby had been given a diagnosis of Down syndrome. I gathered information from 13 fathers whom I interviewed. I had chosen this design because I wanted to hear the stories of participants in their own words (Anastas, 1999).

I recruited using a snowball sampling beginning with fathers I knew through various human service professionals and colleagues. Also, I sent out recruitment letters e-mails (Appendix A) and fliers (Appendix B) to these fathers and colleagues. I asked people who knew a father who might be interested in participating in this study to refer that father to me. Initially I worked on recruiting fathers in the western Massachusetts area and I connected with participants who lived outside of the area. The Massachusetts Down Syndrome Congress (MDSC) assisted me by circulating my recruitment letter via their MDSC listserv. When potential participants contacted me, I asked them questions for screening (Appendix C) over the phone or e-mail to determine if their biological child was born with Down syndrome in the United States in the last 15 years. Additionally the father must have interacted with the western medical community regarding their child's birth. If the participant met the criteria, then we scheduled a time and place for the interview. If the participant did not meet the criteria for participation, I thanked him for their interest but did not interview him. I worked to include diversity through ensuring that my recruitment e-mails and fliers were distributed amongst organizations that serve people of

color as well as people of varying economic status. My research was limited to participants who spoke English.

I interviewed six people outside of the area on the phone. I met in person with seven participants who lived close by for face-to-face interviews. Face-to-face interviews were conducted at a quiet place in a public area such as a library or a cafe.

In an effort to safeguard information I removed names from any content that referred to participants. I used codes instead of names. Also, I kept signed Informed Consents (Appendix D) separated from any completed instruments or recorded audio data.

I ensured confidentiality for all participants involved. My research advisor had access to the data after identifying information had been removed. I have disguised illustrative vignettes and quoted comments.

I stored data in a secure place. All hard copy data has been secured in a filing cabinet that has been locked with a key. The filing cabinet has been kept in a secured place in my home. All electronic data has been stored in a file on an external hard drive on my computer. The electronic data has only been made accessible by use of a password. All data will be kept secure for three years by federal regulations, after three years, all data will be destroyed or it will continue to be kept secured as long as I need them. When the data are no longer needed, I will destroy the data. Please review the letter Smith College School for Social Work's Human Subjects Review Approval letter (Appendix E). I provided the national NASW referral service website address for people outside of the western Massachusetts area as part of the referral list (Appendix F).

I collected data for the study by audio recording (and then transcribing) the interviews. I utilized an interview guide that included a list of demographic and open-ended questions (Appendix G). The length of the interviews ranged from approximately forty to ninety minutes.

Of the thirteen fathers who participated, twelve were married and one was divorced. Twelve of the thirteen participants were white. The other identified as Latino. Participants lived in Texas, Wisconsin, Indiana, Connecticut and Massachusetts. Eight of the thirteen participants' children were born in Massachusetts. Two of the thirteen participants' children were born at home and the rest were born in a hospital. Participants ranged in age from twenty-nine to fifty-four years of age, with the average age being forty-two. Eight of the participants had sons who were born with Down syndrome where five had daughters who were born with Down syndrome. Eleven of the thirteen 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 did not have any more children beyond their one child with Down syndrome.

CHAPTER IV

FINDINGS

This chapter explores the findings for this research study. Fathers reported on their experience of the receipt of the news of a postnatal diagnosis of Down syndrome, resource sharing; recommendations for improvement, the feelings they experienced, and the effects of prenatal speculation of a diagnosis of Down syndrome on the postnatal experience.

Fathers shared a variety of issues and concerns on how the news of a postnatal diagnosis of Down syndrome was delivered. Fathers reported that receiving information, resources and referrals to Down syndrome support groups or organizations, as well as meeting other parents of children with Down syndrome, was very important.

Receiving the News

Fathers shared a variety of issues and concerns on how the news of a postnatal diagnosis of Down syndrome was delivered. They commented on who delivered the news, what was said, the quality of their overall experience in the hospital, their partner's reaction—as well as the tone in which the news was delivered.

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 as well as how they felt in relation to what words were used, as well as the tone and affect of the medical professional(s) they worked with. Also, important to note, fathers 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 how difficult it was to have someone he didn't know give him the news of his child's diagnosis:

...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 Neeew Yoooork 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 "*okaaaaaay, 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 by the messenger's delivery of the news at a doctors 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 wallop message, we're going to deliver, how can we make this easy?" It just felt like it was a typical doctors 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.

A 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 obgyn 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, “its also known as Down syndrome” and that was as you can imagine that was...(sighs) you look back and you think it was sad or horrible. Or the times that your world stops or that you can almost hear the echo of the heart beat in your head that was certainly one of those times.

He continued:

[The] doctors asked that I sit down. Apparently I must’ve looked like I was white or dizzy or something cause they both kind of looked at me concerned and ask that I sit down and they went and called the nurse to get a glass of juice or something so maybe I looked a little off my rocker I don’t recall anything other than what they said that sort of stopped the world feeling, where you hear your own heart beat moment of incredible isolation that you feel when you’re hit with something that you’re completely unprepared for so I sat down and I don’t remember a whole lot of the rest of the conversation other than when it was all kind of a blur in fact the next couple of days were kind of a blur I think.

He elaborated on the positive aspects of his experience:

The doctor who had a son with Down syndrome, the neonatologist, it was an enormous plus to have him to be able to say that to us in that room. It wasn’t like they had to go find someone and bring them in. The man standing in front of me who just gave me this news was in the same situation that we just found ourselves in looking back that was a stroke of good that you couldn’t have planned so that was an incredibly lucky welcomed situation. ...It was good it was very very good. Our OBGYN was very compassionate and very understanding it was presented as an apology almost and I guess, only we who are initiated and understand what life is like with a child like ours can really understand the joy of it at that moment you are not prepared you don’t know what its going to be. You just think your world has ended and in fact just like that very good poem about Holland... You’re world has just changed but it has not ended it hasn’t gotten worse, you have no idea what [is] about to happen. But it is not a death nell. It is not the horror you probably feel the moment that you get the news.

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, lets 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.

He went on to explain:

And it was, “alright what do we do next?” The thing about it too is afterwards when all the nurses when they all knew right away I just kept saying, what are you talking about? She’s beautiful! The girl is beautiful!” And I didn’t feel like I was just being a dad. After talking to [the doctor] I didn’t feel like, “Oh My God! My child has Down syndrome!!!!” We were lucky that we had the doctor’s approach with the positive manner that he did. [The doctor] approached it in a positive manner. I think if he [had been] negative about it, it would’ve affected me in that moment. But certainly dealing with it in that moment, it helped me deal with it, it helped me to get on the phone and to tell family and friends and to tell them what was going on. I think his very positive attitude made all the difference versus some of the stories I’ve heard of just a very negative approach like, “I’m sorry to tell you” or something like that. He treated it like, “Hey aren’t you lucky you have this child!” And we’re probably in the minority from all the people we’ve spoken to.

Receiving the News Together

Many fathers reported that the diagnosis of Down syndrome is often delivered when the father is not in the presence of his partner. Fathers said they would like to receive the news in the presence of their partners.

One father described his experience of how the news was delivered and how he received the news from his wife. He wished they could have received the news together:

So, long story made short, come round back to the facts, he was born around 6 PM, everything was fine, my sister-in-law was here to help us out, and she's watching my daughter while I was there for the birth and they came, and visit and all, and that was

great. And then I went home for the night and stayed at home with my sister-in-law and my daughter, while my wife was still in the hospital, and then basically when the doctor came in for rounds at like 6 AM, the next morning was when he pretty much told my wife “I think he looks a little Downsy” like that was the quote, “a little Downsy.” Then he said, “obviously it is not definitive but he has some of the visual indicators and obviously its not definitive until we do some genetic testing which will take a couple of days, but from that and from looking at the muscle tone, when you know, I don’t know if you’ve seen the testing with the arms to see how quickly they react...” [then] he said, “I’m pretty sure he has Down syndrome.” But it was probably far more traumatic for my wife having to hear this by herself, so of course she calls me at home in tears at 7 in the morning and that’s how I found out...I was at home with our daughter and my sister-in-law, and that’s how I found out (voice breaks).

Another participant described his experience of receiving the news in the hallway after running downstairs to make a few phone calls to tell his friends and family about the birth:

Her birth...and...it was really sweet...I...ran downstairs to call everybody and I made all the phone calls and at first I went with her and I went downstairs and made some quick calls and then I went back upstairs and as soon as I came up the hallway all the nurses were gathered around and then there was a surge in the hallway and then I looked up and then they all scattered and then they looked at me and said, “Mr. _____ we think your child has Down syndrome and we’re running some tests,” and I asked if she was okay, I said, “lets go tell my wife.” I kind of took a big breath, and [said], “Lets go deal with this.” And they said, “we already told her.” So, I went to recovery and of course, and of course the nurse was falling apart, she was a really sweet lady. I was pretty pissed off at the doctor. The doctor gave some bullshit about, “oh well...you fathers are so, we never know how to get a hold of you.” I mean, we had a conversation, I left, I had written my cell phone number down before I even left the room.

The Experience

Some fathers reported that the postnatal experience was horrible while others described it as 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 directed and 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, the same thing [for her too] she started crying right away.

A father reflected on having to go back and forth from having had a homebirth 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.”

While reflecting and crying, a participant described how he felt during the postnatal period. When I asked if the experience of the postnatal period was traumatic, he said:

Yeah, it was. And I went home and I just cried in the shower... I was just crying... And then I'd say I had three occasions in my life where I really sobbed like that... and one was when my mother [was very sick] another time was when my mother [was very sick again] and then that was the third time. But each time I had my cry and I'm kind of healed, and now you kind of moved forward you know, and so I went back to the hospital and what could we do. They had given us ten things you look for, and my wife and I every time we looked at the baby we sort of look at the toes cause they said there is a space between the toes, and we'd look at his eyes. It was a time that I feel we were robbed of a birth. And I think that's the thing, and I'm glad that it was our second child. Although we've had friends who had second children who were neuro-typical[ly] [developing children]. [They] said its' so different because you almost don't know what to do. Its like moving into a furnished apartment and instead of buying the furniture and everything its' all kind of done for you, instead of rushing the baby from one doctor to another and worrying about this and that. We just spent three days looking at our son and everything. We waited two weeks for the results to come back, but by the time the results came back, we knew.

A 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 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 reflected as to whether or not he had been congratulated at the birth of his daughter:

No, I think it could have been much more of a celebration...could have been much more optimistic...you know it would've been nice if someone said, "you guys are going to figure this out and your daughter is going to be healthy and you are going to get to have lots of opportunities." We didn't get that.

One 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 your 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."

A father reflected on what happened when he posted a birth announcement on a Down syndrome listserv that he joined shortly after his son's birth:

My wife went on netscape (one of the things that we don't see anymore) and she found some groups. She found a Down syndrome resource group, and I said, "post a birth announcement," and so she posted our son's name and that he was born. We got 75 messages, and those were from parents, so it wasn't from the medical professionals. Yes! And that was when we started, yeah that really got us going!

Information, Resources and Referrals

Fathers reported that receiving information, resources and referrals to Down syndrome support groups, or/and organizations as well as meeting other parents was very important. Participants expressed 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 and symptoms of fear and anxiety were diminished when fathers had the opportunity to become an agent of change in a situation 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 child's life. Furthermore, it was vital that fathers were supported so they could provide the specialized support that their children would need.

Resources

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 whereas some fathers didn't want resources or found resources on their own. Some fathers could not remember if they received resources because the entire postnatal experience was so overwhelming.

One participant discussed whether or not information, resources or/and referrals were shared at his child's birth:

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 have anything, and finally we talked to a lady and she 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 vague yet positive effect of receiving resources during the postnatal experience:

I do recall it was a starting point, so yeah, I wouldn't say that they didn't have *anything* it wasn't like we were sent on the way with nothing. I felt pretty good [even though] we were leaving there with again, the unknown. But I believe it was the initial set up. We had a path, we had an initial path and we had enough resources to kick start us. And again you take me, my wife...she's fairly educated...and she's got her experiences. And I think that like anything, the challenges are great and its depending on the person too, and the needs of what the couple are, and maybe somebody else would need a little more hand holding, but I feel like we got enough resources to get us going.

A participant explained that it was difficult to remember if he received any information, resources or referrals:

Yeah, I don't remember what they were and I don't remember at least in those very first moments having brochures or anything like that. I think we got a couple of phone numbers maybe, but my wife, if there was any of that then my wife handled it. I'm sort of a poor person to ask about that.

One father described receiving resources in place of his request to talk with another parent:

They gave us one of the biggest packages it was too much info. We didn't open it we didn't even 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.

Peer Support

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 while some who did receive referrals did not hear back from the referral for a long period of time.

A father explained his desire to have had the opportunity talk to another parent and his frustration with the delay in hearing back from the referral:

Yeah, it took forever. Like if they ever wanted me go down to the hospital and meet a brand new parent I'd be there in five minutes, no question about it. And, not that I'm going to stop their problems, its just to say, "look you're in a really bad place now...here is my son...they turn out ok and like with any kid you're going to face some challenges." And I mean that's how I'm envisioning the process should work and I still to this day don't know if that is how its suppose to work, I don't know but we were given some cursory information about that. But whether we dropped the ball, or they dropped the ball...I'd like to think, I really don't know, but I know in hindsight they were having some issues with the person that was managing volunteering and that kind of thing, and I understand that they're a volunteer group, so I don't want to be totally negative, but...I would've loved to just hear from any parent who's got a kid with Down syndrome. I don't care if they're a trained professional...I wasn't looking for someone with a counseling degree to come in and deal...I would just talk to the parents about what its like, and what am I going to deal with the next three months? What am I looking at right now? And then we'll sort the big picture stuff out later.

This participant started to respond to the question of whether or not he received resources. His reply then transitioned to his reflecting on the experience of talking with another

father and the significance of that experience. Part of this quote had been referenced in the section earlier in the findings chapter that explored the importance of congratulating fathers. This quote is referred to here again (although with more context) to illustrate the importance of talking to another father during the postnatal period:

Participant: ugh she tried...she's not very good on the Down syndrome thing. She told me to e-mail the [local] Down syndrome [organization] and I did, and Sam Brown, have you met him? He's just like an uber dad and his wife is amazing, he called me up within like 5 minutes of the e-mail.

Researcher: How did you feel when he called you?

P: I was surprised and he said, "Congratulations" which was the coolest thing anybody had said...

R: cause no one had said it before hand...

P: (quiet crying...)

P: yeah, Sam was really cool (voice quivering starts crying a lot more...and some time lapses while he cries)

P: But that was really cool and he talked about his son who lives between here and [the next state over]...he's [in his early twenties], he likes beer, he goes to community college, he has a job...that's better than most of my friends [(and starts to laugh)]. He tells me about things-he's got a short temper, he's kind of a pain in the ass this 21 year old, but its' not so bad.

One father who received a referral to meet with a family replied to the query as to whether or not he was given a referral: "Yes, and 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."

This next quote from a participant best illustrates the benefit of meeting with someone who can identify with the experience. This father described the experience of connecting with a grandmother of a child with Down syndrome after his own child was born. He explained:

I think just a day or two after we got the conclusive news, we saw our neighbors who are really wonderful, so we told them and we looked pretty bad off I think, and she, the woman in this couple said, "I've got a good friend who's grand-daughter has Down syndrome and all, and she is a nurse and she works in the medical profession, I'll just have her come over, it might be nice to talk to her." It was so nice just for her to offer that, and this woman came and it was like she became my grandmother instantly or like my mom or something and she was here maybe an hour or something, and basic stuff, and I cried on her lap. I'd take anybody at that point and anybody who sort of hold their arms out to me, so that was huge that was a key moment, where I felt like somebody is helping me and it is helping me and it is helping, they're not just making the gesture... ah, and [they] knew what this was.

The same participant continued later in the interview to reflect further on the significance of meeting with someone who could identify with his experience. He perceived this visit with a grandmother to be a greatly improved experience compared to how the news was initially delivered by medical personnel:

I think about that woman who came soon after, basically to kind of a second chance at dealing with this in a way that felt more right to us. She could answer a bunch of questions she could say, "yeah you know this wasn't easy for me either." So she wouldn't just dismiss our feeling but she'd also alleviated or mitigated our fears as well. Like, "you know what, I totally love my grand daughter she's great you know... we'll get them over here and you could meet her." And it was sort of very pragmatic and she knew all the right things to do, and so, I think that would be ideal for sure.

Another father recalled his experience of meeting with another father of a child with Down syndrome. He was friends with the father prior to his child's birth:

Some friends of ours who lived close to the hospital, I called the husband. He came over, that [same] day. Having him to come over and talk to me and my wife, and it was probably way better, somebody you know, than any clinician or any expert.

Fathers' Emotions

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

Initial Feelings

Participants discussed the range of emotions and shifts from feeling excited about their child's birth to overwhelming feelings of fear and anxiety. Fathers shared their feelings as it related to possible medical complications (i.e., heart condition) that could lead to emotions of intense fear regarding the unknown outcomes of life or death for their newborn, their child's future, disability oppression; sibling issues, fear of life-long dependence, vulnerabilities and education.

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.

A father described his experience within the context of his religion and spirituality as a guiding presence through those early stages of his son's birth:

I know this is all in God's great master plan, but I did have a tear in my eye. Its funny that I did that but, devastation is not the word it is absolutely not the word, foreign, yes. So devastation is not it, shock maybe a little shock but immediately, I remember immediately like within days going to work and announcing it to the people I worked with. Some were in Texas and I just put out an e-mail that, "yes my son had been born and yes he had Down syndrome please, feel free to congratulate me!" Right from the get go.

For some fathers their sense of identity and other messages internalized from a "doing culture" affected their feelings and process about their child. A participant explored his own identity as a father and how his son's diagnosis challenged his value system and self-identity:

This just happened because there is the possibility that [this] happens. But, my fear was, "how I can deal with this?" I feel that also my fear was not just about my son, [it] was about me, because I feel that there is some kind of social issue about having a son with this kind of syndrome. So, maybe [it was] my egocentrism, vanity maybe. Because yeah, in some ways my first son made me feel proud.

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 family. This 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.

He continued:

I was confused. This was before they finally told us. Before they confirmed it, which was about an hour later. But in the meantime, ten minutes after he was born till an hour later I was confused. I was really mad. I didn't know how this had happened. I didn't know who to blame. I was acting irrationally. My wife was very upset I remember trying to break the news to my father that I had a boy and all I could say to him was, "there [is] something wrong with my son.' That was the first thing I said to my father, (voice breaks a bit) when my son was born. Because we didn't find out if we were having a boy or a girl so... a bit shattered. When I came in and I saw that there were two doctors in the room, after I was gone from the room for a few minutes, and I came back. I knew that that was basically confirming what had happened. They explained it to us. I, at that point decided to choke down my emotions and try to be the stronger of the two of us, and be supportive for my wife. It took me about a year to talk to anyone about it. I choked down my anger more so than anything. I just needed to be supportive for my wife. I needed to assure her that everything was going to be okay, that we'd get through it. That we would provide anything that was needed for our son because he was our son and we love him and wanted to give the best care, the best anything he needed. And that, things would be okay. I'm from a very emotional family and I'm very emotional but I can also quell my emotions quite easily which kind of back fires because eventually they erupt, they explode and you don't want to be near me for a couple of days when that happens.

A father discussed his feelings of the postnatal period that also involved open-heart surgery shortly after his son's birth. The participant was in another country when his son was born. He discussed his experience of meeting his son for the first time during the postnatal period:

I was [feeling] cold because what my wife said to me was that he was in an extreme situation and maybe he was going to die. So, the uncertainty was high. I tried to lower my expectations in many ways. So when I saw him at this time I was not sure about what was going to happen during the surgery. I didn't want to get involved emotionally, but at the same time, was the other problem that he got this syndrome...Down syndrome. I didn't know what was going to be my reaction if he just got the heart problem and not the Down syndrome. Sometimes that would happen. My sister told me that so I think that moment I overcome that kind of limitation [or] restraint that I put on my feelings.

...[Hugging my son] was strange. It was like slow process, then I feel this is my son. It was a slow process and then for the rest of the days before the surgery, I started to have this physical contact, [I was] feeling, this is my son.

He continued:

Those days were like a storm in my life, but what is incredible is that we survived. That I remember the surgery took five hours. Initially, the doctor said this is going to be between two and three hours, and then this took five hours. I was crying when we were in the waiting room, thinking the worse because...five hours.

A portion of the same quote for this participant was cited in an earlier section of the findings chapter. The quote is being used again with more detail to illustrate how he felt regarding the *entire* experience rather than one aspect that was relevant to the previous section as well. This participant described how he was feeling when he received the news:

I got to say it was a shock, right at first. It hit me like a ton of bricks. It was a shock, and [for] my wife [as well,] the same thing. She started crying right away. I was suppose to be there, for her, but I didn't even really stand up. And there was a nurse, her name was M and she was congratulating us. She actually made me feel better. She was coming to check on us constantly, to see how we were doing. I guess my first thoughts were, "lets put her back and try again" and I hate to say it, but I thought it. I remember thinking, "why don't we do this over and so that she doesn't have Down syndrome." It was really at first, two-three days before we got home, and settled in at home with her. Is there anyway? Do we know her yet? Until we got home and settled, between that and being with my son, those were the things I thought of the whole time...It was a variety of different feelings. There was feeling afraid and not knowing what her future would be, knowing that she's going to have to work that much harder at life in everything—and, that was probably one of the big themes. Just wondering about her future. We're doing everything we think we can to make things easier for her.

A father described his feelings of learning of his child's diagnosis of Down syndrome four months after his child had been born:

I was pissed! I would say that I don't have a lot of trust in the medical profession to begin with. My degree is in science and I understand medicine to a reasonable level. Also, being science minded I want to understand how things work so, you know I was quite confused as to how so many individuals, so many avenues, so many opportunities to potentially flag that were missed and dropped. I never got any quality answers from anybody relative to that and how [the doctor] reacted was marginally apologetic. But

basically he just sat there and let me vent and what I was clear on is that it was a pretty big instance of the ball being dropped... Out in left field, from the standpoint of, "what the hell are you talking about."

Some fathers reported feeling very protective and defensive of their newborn. A

participant described how he felt:

I don't know I just kept telling myself to own the situation regardless of what it was. I was really sad. I was almost like, defensive. I didn't want anyone to apologize. I felt more protective than anything, of my wife and of my son. That [is] probably the main emotion, just really hyper protective, like almost aggressively.

Another participant described a similar yet more general sense of feeling protective after his child was born:

I felt that everything was, "yes, but... you know... he [is] my baby, but he has Down syndrome" and "he [is] my new little boy, but he has Down syndrome but you know," or even if I'd be in downtown at the coffee shop or something people would be like, "oh you have a baby I just want to see" and I felt like [saying] "leave him alone." I thought that they would judge him. You know like he was an infant, nobody could tell he had Down syndrome. But I was I just wanted everyone to leave us alone. And then what happened is that you just started bonding with the baby.

Fear

Participants discussed their feelings of fear and what issues came up for them when their child was born. Fathers discussed their feeling of fear as being the driving force to their feelings of sadness, anxiety and anger. The fear that fathers described was essentially the fear of the unknown. Fathers felt less fear (thus less anxiety, sadness and anger) when their fears were abated. 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:

Yeah, sadness and again the only thing I ever fussed on was the baby. And then 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 its' 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. And again maybe its shorter-term cause the way you have to think about 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. All I know is you have babies and they grow up. I think anger is a fair word, "Why me? Why am I getting this? Why are the cards being dealt to me this way?"

A 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."

A 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 its 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 he has Down syndrome and that he 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.

A father whose child was born at home, discussed his feelings as it related to fear and other emotions that he felt after he received news of the diagnosis:

Yeah definitely! Fear that I would continue to be fearful when getting the news. I remember the friend who was actually the wife of the guy who was so kind and she was like you know you'll have joy again and I was just like, "no! no I won't this is the end!" I don't know the fear thing again was I was afraid that I would be afraid and that I wouldn't get over being afraid that this would sort of be like torture or that I wouldn't get use to it. Which seems so silly now cause I got use to it so fast. But at the time it was like, "you guys just don't understand people with Down syndrome kind of wig me out a little bit I'm not the person who's going to be able to handle this." And so feeling that was the

case and I'm thinking oh my god the rest of my life I'm gonna have to be this person who's sort of anxious scared, awkward, depressed, worried I just felt like all these negative feelings are just going to obliterate this happy world that I thought was going to be gone. So it was just a bunch of fears. Like there was a different dimension to it but certainly all about fears or that I've done something wrong. Or, I wasn't going to arise to the occasion.

Insensitive Comments

Some participants described their feelings regarding otherwise well-intended comments, that are often experienced as oppressive and insensitive by many fathers. Insensitive comments often perpetuate stereotypes as well as feelings of pity, which often generate a feeling of shame for new fathers.

Comments such as what this father described perpetuated stereotypes about people with Down syndrome. This father 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. [It] was to the point where I did talk to the hospital administrator and just said that she was in the wrong in how she handled it.

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 visited] who 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."

Prenatal Speculation

Five of the thirteen participants reported on the experience of speculation or concern of a possible diagnosis of Down syndrome prior to their child's birth. Fathers would often discuss this in the beginning of the interview because the prenatal speculations often informed (in part) their emotional response to when they received the official postnatal diagnosis of Down syndrome.

Fathers expressed the shock they felt after receiving a postnatal diagnosis of Down syndrome, when all pre-natal testing results had come back negative. Fathers reported a variety of pre-natal experiences that effected how they felt when they did receive the official postnatal diagnosis.

Participants reported that their obstetrician gynecologists recommended that they go through with the tests due to certain indicators (i.e., maternal age) that could possibly increase the chances that their child would be born with Down syndrome. Some obstetrician gynecologists did not give families information as to why they recommended pre-natal testing.

A father recalled his daughter's birth and the reaction of the medical staff around him. He referenced the speculation from the prenatal period as to whether or not his daughter would be born with Down syndrome. The parents were told that they did not need to worry about Down syndrome after some prenatal testing results came back negative. He explained:

My daughter was born about 8 o'clock the next morning, and right when my daughter was born, right when she came out, it was a bad experience. She came out and the nurse took her right away, and took her right over, and started. And then the doctors showed up and walked over there right away. I thought it was kind of weird, but then he came back and said, "Your baby has Down syndrome." And it was with all the testing and everything they had done before for them to say it wasn't and then now it was Down syndrome. It was quite a shock for my wife and I, and we, well there was a lot of commotion going on all of a sudden...After the first couple of days, and the nurses, there had been only one nurse there that had been, been nice, whereas the rest of the people

were acting like my daughter didn't even survive, and they were apologizing and everything else. And we were like, oh well our daughter is still our baby don't apologize. And one nurse, and, we sent her "thank yous," and [she] was congratulating us and she was excellent. But the rest of them just acted like she didn't survive the birth...and that made it that much harder.

Another participant described his experience the day before his son's birth at a routine ultrasound with his wife:

My wife had been talking to the tech about what are the chances of losing your baby as the result of the amniocentesis. I want to say that she said one in three hundred or something pretty high. And [then] my wife said, [if] the chances are one in whatever and then I don't want to do the amniocentesis right then and there. The doctor tried to talk her out of it and [then] my wife said, "We would keep the baby regardless." Then the doctor said, "this is what a lot of people say, but then they get a diagnosis [and] they started to sing a different tune." The [doctor went on to say,] "One out of three hundred babies have Down syndrome." Or something like that and she said, "you're my 299th and you might be the one." My wife said, "Well, we are out of here."

A participant described his experience of prenatal speculation that involved poor communication on the hospital's part. He explained:

I think [the hospital] actually lied to us. They're a Catholic hospital, which isn't necessarily a good or bad thing, but, at some point when they were doing the ultrasounds, they were concerned. They wanted us to come in every week, but they said that it was normal. In retrospect, that's a little odd. They were also doing 3D ultrasounds, which you just don't do unless there's something more complicated [going on.] But they kept saying everything was fine. I don't think we would've terminated or anything, but I think that was their concern, that we would've [terminated the pregnancy.] So, I think our communication at [the hospital] was sort of shitty. Our midwives, they were awesome. They were really supportive after the birth and everything else. But with the actual physicians at [the hospital] I think the communication was weird. And after he was born he got jaundice pretty badly so we had to go to the hospital which is what we were trying to avoid in the first place. I think communication there was pretty terrible too.

At the beginning of the interview a participant expressed that he thought it was important to include details of the prenatal experience before he talked about the postnatal experience. He explained:

It might help to paint the picture for you a little bit before hand. It took several years for my wife to get pregnant, one miscarriage etc...so, we were very happy to finally be pregnant. My wife, I remember, it was around the fourth month and she went for the alpha fetal protein (AFP) test. At the time nobody represented it as much of anything as standard test to do. When they called my wife up with the results they just sort of threw it out there that it was positive for Down syndrome. We didn't know what that would mean. We were told that it was not a very accurate test. So, we talked it over at the time, and I would say that the doctors were marginally helpful. They said that the only way to know for sure is to get an amniocentesis and there is a risk in that. Why should we risk the health of our child just to find out something we are going to find out eventually? So, then they suggested that we go to this doctor who was world renowned in doing these ultrasounds, these high-end ultrasounds. I didn't really want to go but my wife did and so we went.

He continued:

[The doctor] declared that all was fine and that nothing was wrong with our child. But, my wife still was convinced in her mind that there was something critically wrong. I had sort of put it out of my mind [and thought] that this was behind me. Nothing to worry about, nothing to deal with et cetera... And my wife was convinced that something was wrong. So the day that my daughter was born and it was a long labor and she actually had some problems in labor. Her head got stuck in the birth canal, her heart rate dropped so they had to quickly get her out of there and they brought in the neo-natal guy. At the same time she was whisked over to the neo-natal doctor right away and checked out and what not, and she was fine. Then the obstetrician called me aside and said, "hey we think we might see some signs that your daughter has Down syndrome," and "could we have your permission to run this test? And we will call a geneticist and check it out." He sort of said it to me in a way that maybe I was sort of still in denial. Well, he's not telling me anything definitive here. He is just saying we should check this out, and I'm looking at my daughter thinking this is the most beautiful creature God ever created. So, this guy must be nuts!

Recommendations

Fathers suggested how things could have been improved during the postnatal experience while they were at the hospital. Participants were deeply affected by the disability oppression that they interfaced with (as manifest in the attitudes of medical personnel) during the postnatal period. This was a time when fathers needed support, yet it was rare that participants felt supported by medical personnel. Some fathers did feel supported but most of them left wishing their experience could've been better.

Overall, fathers felt strongly that hospitals should be more prepared and that medical personnel should have better training when it comes to delivering a postnatal diagnosis of Down syndrome.

Fathers were asked as to what they would want to recommend to a new father. The recommendations to new fathers from participants who have been through the postnatal period are also shared in this section.

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 its not."

Another father explored how the whole experience could have been improved if there was someone around at the hospital who had firsthand knowledge as a parent, guardian or caregiver of a person with Down syndrome:

I mean at least in theory cause I don't know I mean 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 hadn't already gotten use to it but when you say that 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 its sort of like somebody you know who can literally relate to what you're going through.

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

I think that maybe somebody...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 its 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."

A participant offered a variety of suggestions to how the postnatal experience in the hospital could've been better:

P: Definitely, we should've been together. [It] would've been really helpful and it could've been a little bit more promising and it didn't have to focus on her heart, or, it just seemed to be like a real negative focus. And just the total delivery by her self, that in and of itself was just unacceptable. It was just a really bad place to start. It was really hard to get past that and I don't know. If things would've happened differently, had we been both there to hear the news. It was so reactive. We didn't really have time to ask the questions. She looked so well [that] her health wasn't a real concern.

R: What were your questions in those moments if you had had the time.

P: I guess 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 use 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 guess 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.

The same participant shared what he would want a new father of a child with Down syndrome to know:

It is [going to] be okay, that is all. That it just might not be easy but that there are people out there to help him and that there is a ton of promise. I think that that is what we wanted to [hear.] [And] just to let them know that everything is going to be al-right.

Other Findings

The final section of the Findings chapter includes a few other findings that were important to include but are not necessarily relevant to the fathers' experience of postnatal support. The other findings include open-heart surgery, superstars with Down syndrome, religion, regional differences, gender roles and process, and devotion.

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 this.

Participants discussed the heart surgery as being a very challenging and frightening aspect of their child's birth—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.)

A participant described the extreme difference from how he felt when they received the news of a postnatal diagnosis of Down syndrome at a hospital near their home, to experiencing a significantly improved and strikingly positive experience at the city hospital where their daughter had her open-heart surgery. He described:

P: The doctor is saying we will be ok and he's happy for us. He doesn't see this as a tragedy at all and it was normal for him. And in fact he pretty much said those words, "I

think you'll find parenting to be much the same as your son." And that was just like music to our ears. [This doctor] was incredible. He was [part of the] earliest and best experience we had there, when we were more vulnerable. But as we kind of went on and kind of prepared for the surgery we dealt with probably forty different people. I remember critiquing every single one of them and my wife and I were like, "well, weren't they nice and oh, I really liked that guy" and "oh, that woman was so sweet she was just fantastic!" I remember saying that about every person who was gentle and patient. They were absolutely being their best selves. They seemed to understand and they seemed to understand that we were fragile. For me, the doctor was my kind of guy. He was soft spoken and there was no male distancing of, "oh, well you're the father!" He was a sweetheart and he would say delicate things in front of me.

R: It sounds like it was night and day in the description from the first hospital you were at to the second hospital you were at.

P: It was really great! But the only down side was, our daughter was having or what seemed like a dangerous or extreme surgery, practically at birth! But other than that it was a bunch of fantastic people.

Superstars

A participant made a very interesting point during an interview. He 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." This is often done in an effort to give parents hope for their children in an ableist society or "doing culture." It would be a practice comparable to when a neurotypically developing child is born. If medical personnel presented the parents with stories about other peoples neurotypical children who went on to become the president of the United States or an Oxford scholar. The message that this gesture conveys was best explained by this father:

And those superstars that we meet, they put in our faces! They're not super and that's the part where you know they are very special in their own ways. But its so important to give families hope but sometimes it is really unrealistic. When you meet a keynote speaker or the first time you realize that somebody's speech and interactions are a lot more scripted than you ever imagined, by their parents. [It] makes me wonder what can I hope for, for my daughter. When someone who has such amazing tools. Whether it is speech or [they

are] cognitively a little more evolved than my daughter—and, I see the supports that they require to be tolerated by society. How hard is it going to be for my daughter? It is frightening (voice cracks.)

Religion

Some fathers who practiced Catholicism as their religion and access to spirituality reported feeling more supported through the postnatal experience as a product of their faith. Whereas some fathers who subscribed to Catholicism as their source of faith, spirituality and religion—experienced their child’s birth as a form of punishment for their sins’. This experience for some fathers gives evidence to the reinforcement of the religious model of disability (as religiosity) and how this model continues to contribute to disability oppression.

Regional Differences

Fathers whose children were born in eastern Massachusetts reported a more positive postnatal experience than fathers whose children were born in other areas of Massachusetts as well as other areas in the United States.

Gender Roles and 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 their 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 expressed that it was very helpful for them to have a space to process their feelings. Perhaps they would benefit if they allowed themselves the space to process. Yet there is much in the way of struggle and pressure for men in this culture.

Eleven out of thirteen fathers cried during their interview at various points when they

reflected on their child's birth. For some fathers this was the first time they explored their feelings about their child's birth, since their child was born.

Devotion

All the fathers were completely dedicated to their children. They expressed incredible if not extraordinary depths of love and devotion to their children. Fathers often explained that despite all the challenges, that they would not want their child to be different. They love their children completely for who they are and just as they are. Participants also reported that their children are doing very well. Most fathers expressed that negative societal attitudes and beliefs about Down syndrome and disability are in great need of change.

CHAPTER V

DISCUSSION

This exploratory study examined the experience of fathers upon the receipt of the news that their newborn baby had been given a diagnosis of Down syndrome, using information gathered from 13 interviews with fathers.

The research with fathers yielded findings similar to Skotko's (2005a, b) 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 from Skotko's (2005a, b) research for mothers.

New ideas that would contribute to the literature were extensive. Fathers elaborated on themes from prior research that would add to pre-existing literature. They shared new ideas as well.

The findings revealed that fathers had a variety of concerns on how the news of a postnatal diagnosis of Down syndrome was delivered. Many fathers reported that the diagnosis of Down syndrome was often delivered when the father was not in the presence of his partner. Some fathers reported that the postnatal experience was horrible while others described it as a relatively supported experience. Fathers who were congratulated and fathers who were not congratulated consistently expressed the importance of celebration at the birth of their child. Fathers reported that receiving information, resources and referrals to Down syndrome support groups, or/and organizations as well as meeting other parents (namely fathers) was very important. Participants discussed a combination of emotions ranging from sad, angry, shocked,

devastated, elated, excited, happy, confused, to feeling relieved, anxious and fearful. Five of the thirteen participants reported on the experience of speculation or concern of a possible diagnosis of Down syndrome prior to their child's birth. Participants were deeply affected by the disability oppression that they interfaced with (as manifest in the attitudes of medical personnel) during the postnatal period.

Overall, fathers felt strongly that hospitals should be more prepared and that medical personnel should have better training when it comes to delivering a postnatal diagnosis of Down syndrome.

The findings from this study as well as the pre-existing research of Skotko (2005a, b) 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.

Skotko's (2005a, b) research with mothers yielded findings similar to this research for fathers. Fathers often experienced the messengers of the news of a postnatal diagnosis of Down syndrome as insensitive and pessimistic.

In many cases fathers recalled that the diagnosis was not disclosed by their obstetrician. Parents were usually notified without the presence of their newborn. Statements of "I'm sorry to have to tell you this..." often prefaced the diagnosis disclosure.

The mothers from Skotko's (2005a) research felt a range of emotions similar to participants from this research study. The mothers reported feelings of shock, anger, and devastation that resulted in mothers 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.

The participants had many suggestions for improvements for medical personnel. Skotko’s (2005a, b) research participants (mothers) shared many recommendations also. Participants (fathers) for this research study shared recommendations similar to the mothers as well as a variety of new ideas.

New Ideas and Recommendations

Access to information, resources and referrals helped fathers to feel supported while creating a feeling of empowerment. The feelings and symptoms 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.

Fathers were deeply affected by the attitudes of medical personnel. This resulted in many fathers feeling stigmatized and traumatized by the postnatal experience. Also, fathers were deeply hurt by the assumptions of medical personnel that their child’s birth was a tragedy.

Many participants found it difficult to talk about their feelings. This difficulty explains why it is so important for fathers to have access to support and resources as soon as they receive the diagnosis. Fathers are at great risk for depression and anxiety as a result of this difficulty.

New Recommendations

Fathers suggested how things could have been improved during the postnatal experience while they were at the hospital. Participants were deeply affected by the disability oppression that they interfaced with (as manifest in the attitudes of medical personnel) during the postnatal period. This was a time when fathers needed support, yet it was rare that participants felt

supported by medical personnel. Some fathers did feel supported but most of them left wishing their experience could've been better.

Participants expressed that they would like to be told of the postnatal diagnosis by a physician they knew. Or, if possible fathers would like the diagnosis disclosure to be conveyed by another parent or in the presence of another parent of a child with Down syndrome.

Fathers would like to be supported during the intense shift in emotions from joy with celebration to fear. Participants identified this need for support as the moment that correlates to the shifts in feeling state, from the time prior to the diagnosis to after the disclosure of a diagnosis of Down syndrome.

Also, many fathers felt that they wanted information, resources and referral as soon as they were told of the diagnosis. They expressed that having information contributed to their feeling less anxious and fearful.

Fathers needed to hear a sense of optimism, hope and facts about Down syndrome from the messenger. They wanted to hear about real people with Down syndrome and not the superstars. They wanted to gain a realistic sense of what they are dealing with so they could have their own process about their child and what it means to them, as opposed to what it means to someone else. They do not want to be met with the unconscious and unexplored negative and oppressive attitudes of the communicators. These recommendations from fathers were directed at physicians as well as nurses and other members of the medical community.

Some of the mothers in Skotko's (2005a) study revealed that prenatal speculation with negative test results contributed to an improved postnatal experience. The mothers felt more prepared to receive a diagnosis of Down syndrome as a result of prenatal testing. Participants for this study who were involved with prenatal speculation reported that they did not feel more

prepared to receive a diagnosis of Down syndrome during the postnatal period. Mothers from Skotko's (2005a,b) study also reported that the physicians were more helpful and forthcoming with information and referrals for support when the mothers had prenatal testing with negative results; the study with fathers and postnatal support did not yield a similar finding.

Fathers for this research study consistently reported a different experience of the postnatal experience with prenatal speculation than did some of the mothers surveyed in Skotko's research. The difference to this factor could be attributed to it being the case that Skotko (2005a,b) drew from a significantly larger sample. Skotko (2005a,b) surveyed thousands of mothers using qualitative and quantitative research methods while I interviewed thirteen fathers using qualitative methods.

Other than this difference in similar literature from Skotko's (2005a,b) research, generally there was not much available in the way of prior research on fathers of children with Down syndrome and postnatal support. As a result there was no obtainable research to compare the findings for this project with findings from previous studies.

Limitations of the Study And Ideas for Further Research

Limitations

The sample size of 13 participants was a limitation for this study. The small sample size did not yield as much data as a larger sample might have. Despite the small sample size, this study lent itself to obtaining depth in the information that was collected.

Also, even though the study was limited to the same 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 contribution to the lack of diversity in this sample is that 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 supports to negotiate. Most participants subscribed to white middle class culture, most were married, middle aged and employed. As a result they had more time for participating in such organizations as well as Internet access. These organizations tend to cater to white middle class culture thus contributing further to the lack of diversity in this sample. Another contributing factor to the lack of diversity in this sample is that I could only interview people who spoke English.

Implications for Future Study

A larger scale qualitative and quantitative study for fathers and a postnatal diagnosis of Down syndrome that is similar to Skotko's (2005a, b) 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.

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 of lack of diversity in this 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 research.

Implications for People Working with Families

Whose Child Has Been Diagnosed at Birth with Down Syndrome

The suggestions, based on comments of the fathers who participated in this study and the mothers who participated in Skotko's (2005a, b) study, are as follows:

- The parents should be congratulated.
- The physician should disseminate the diagnosis as soon as he/she suspects it.
- The physician should give the news with both parents present.
- The physician should refrain from prefacing the disclosure of the diagnosis with, “I’m sorry...”
- A physician should convey the news.
- The physician should be a doctor who the parents know.
- The news should be delivered in a private setting.
- The newborn baby should be present.
- Up-to-date information, resources and referrals to local support groups should be provided.
- Hospital staff should coordinate a connection with a parent volunteer within the first 24-48 hours of receiving the diagnosis.
- Physicians and medical personnel should refrain from sharing any insensitive, pitying and shaming comments. As well as any personnel opinions.
- The physician should integrate positive aspects of Down syndrome when describing the diagnosis.
- Physicians, medical personnel and social workers should check their bias.
- Physicians, medical personnel and social workers should not perpetuate disability oppression as manifest in stereotypes about people with Down syndrome.
- The physician should be thoughtful, present, empathic and sensitive regarding the language they choose when disclosing and explaining the diagnosis.

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 when returning home from the hospital. They felt it didn't take long before they were accepting their child's diagnosis and felt ready to move forward to learn about the resources and supports they would need to support their child. It seemed that a contributing factor to their feeling better at home was that they were not interfacing with the effects of disability oppression because they were no longer in the hospital. Inevitably they dealt with oppression in many other arenas and will sadly continue to do so, but at least in these early stages, fathers identified home as a kind of necessary respite from the hospital experience.

Fathers need more support during the postnatal period. Fathers identified that talking with another father within twenty-four to forty-eight hours of receiving the news was inexplicably helpful.

Institutions such as hospitals and schools perpetuate disability oppression through the attitudes that inform policy, and vice versa. 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 with 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 when it comes to delivering a postnatal diagnosis of Down syndrome. The Prenatally and Postnatally Diagnosed Condition Awareness Act was passed as a result of Skotko's testimony prepared for the Down Syndrome Congressional Caucus on February 26th, 2009. 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).

It has been less than two years since this bill was passed. There is a great need 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. The hope is that parents would feel supported and empowered during the postnatal experience as a result of the thorough implementation of the Prenatally and Postnatally Diagnosed Condition Awareness Act.

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Appendix A
Recruitment E-mail

Hello! :-)

I am a graduate student at Smith College School for Social Work. As part of my MSW thesis I am researching the experience of fathers of children who were born with Down syndrome.

If your child was born within the last 15 years please consider participating in this study by taking part in an interview that will last approximately 60 to 90 minutes.

If you are interested in participating in this study or/and obtaining more information please contact:

Desiree D. Lowit
(xxx) xxx-xxxx
dlowit@smith.edu

Yours truly,
Desiree D. Lowit

Appendix B

Recruitment Flier

Down syndrome/Trisomy 21 Research Project

**Are you a father
whose child was born with
Down syndrome/Trisomy 21?**

Was your child born within the last 15 years?

I am researching the experience of fathers of children with
Down syndrome as part of my MSW thesis at
Smith College School for Social Work.

If you are interested in participating in this study and/or if you'd like
more information please contact me:

Desiree D. Lowit

Phone XXX-XXX-XXXX

e-mail: dlowit@smith.edu

Appendix C

Screening Questions

- 1.) Was your child born within the United States?
- 2.) Is the child your biological child?
- 3.) Was your child born within the last fifteen years?
- 4.) Did you interact with the western medical community regarding your child's birth?

Appendix D

Informed Consent

Dear Potential Research Participant,

My name is Desiree Lowit, and I am conducting a study of the experience of fathers upon the receipt of the news that their newborn was given a diagnosis of Down syndrome. The study is being completed for my MSW thesis at Smith College School for Social Work. The data collected may possibly be used for future presentations and publications.

You are being asked to participate in this study if (a) you are a father of a child who was born with Down syndrome; (b) your child was born within the last 15 years; (c) your child was born within the United States of America; (d) you had some sort of interaction with the medical community regarding your child's diagnosis. As a participant in this study you will be asked to be interviewed in-person. The interview will last approximately 60 to 90 minutes. The interview will be audio recorded, and I will transcribe it in order to ensure accuracy of your statements. The interview will not be audio recorded if you do not wish it to be. You will be asked questions that relate to your experience upon the receipt of the news that your child was given a diagnosis of Down syndrome. Demographic data will also be collected.

The potential risks of participating in this study are the possibility that you might feel strong or uncomfortable emotions while reflecting on your experience of receiving the news that your newborn had been given a diagnosis of Down syndrome. In case you feel the need for additional support after participating in this study, you will be given a list of resources for mental health services in your area.

You will receive no financial benefit for your participation in this study. However, you may benefit from knowing that you have contributed to the knowledge of the experience of fathers upon the receipt of the news that their newborn baby has been given a diagnosis of Down syndrome. It is my hope that this study will help social workers and medical professionals to have a better understanding of how to work with fathers upon the receipt of the news that their newborn baby has been given a diagnosis of Down syndrome. You may also benefit from being able to tell your story and having your perspective heard.

Strict confidentiality will be maintained, as consistent with Federal regulations and the mandates of the social work profession. Confidentiality will be protected by coding the information and storing the data in a locked file for a minimum of 3 years. Your identity will be protected, as names will be removed in the analysis of the data. Your name will never be associated with the information you provide in the interview. The data may be used in other education activities as well as in the preparation for my Master's thesis. My thesis advisor may read some portions of the transcribed interviews, after identifying information has been omitted.

This study is completely voluntary. You are free to refuse to answer specific questions and to withdraw from the study at any time by contacting me by phone or email. If you decide to

withdraw, all data describing you will be immediately destroyed. You have until March 30th, 2010 to withdraw from this study. After that time, the information from the interviews will be integrated into the thesis. If you wish to contact the chair of the Human Subjects Review Committee at the Smith College School for Social Work, you may do so by calling (413) 585-7974.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

SIGNATURE OR PARTICIPANT

SIGNATURE OF RESEARCHER

DATE

DATE

If you have any questions or wish to withdraw your consent, please contact:
Desiree Lowit , XXXXXXX, dlowit@smith.edu

Thank you for your participation.

Please keep a copy of this form for your records.

Appendix E

HSR Approval Letter



Smith College
Northampton, Massachusetts 01063
T (413) 585-7950
F (413) 585-7994

February 16, 2010

Desiree Lowit

Dear Desiree,

Your amended materials have been reviewed and they are now in order. We are glad to give final approval to your study.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project.

Sincerely,

A handwritten signature in cursive script that reads 'Ann Hartman'.

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Mary Beth Averill, Research Advisor

Appendix F

List of Resources

National Resources:

National Association for Social Workers (NASW)

<http://www.helppro.com/nasw/BasicSearch.aspx>

Websites:

Dads Appreciating Down Syndrome

<http://www.dadsnational.org/>

National Down Syndrome Society

<http://www.ndss.org/>

National Down Syndrome Congress

<http://www.ndsc.org/>

Local Outpatient Mental Health Clinics:

Child and Family Service of the Pioneer Valley

Website: <http://www.chd.org/cfs/>

367 Pine Street

Springfield, MA 01105

e-mail: CFSinfo@chd.org

Tel: 1-800-232-0510

Carson Center

Website: <http://www.carsoncenter.org>

77 Mill Street, Suite 251

Westfield, MA 01085

Tel: (413) 568-6141

Tel: (888) 877-6346

Valley Psychiatric Service

Website: <http://vpsi-ma.com/>

511 East Columbus Ave. □

Springfield, MA 01105 □

Tel: (800) 593-9222

Local Area Resources:

Massachusetts Down syndrome Congress

Website: www.mdsc.org

Tel: (800) 664-MDSC

The Down syndrome Resource Group of Western Massachusetts

Website: <http://www.dssupport.org/>

Contact Person: Tanya Wheeler

Tel: (413)-562-7395

E-mail: Tanya.wheeler@comcast.net

Department of Developmental Services

One Roundhouse Plaza

Northampton, MA 01060

Contact person: Dave.Chevalier@state.ma.us

Tel: (413) 586-4948

Whole Children

Website: www.wholechildren.org

Tel: (413) 585-8010

Appendix G

Interview Guide

Demographic/Short Answer

How old is your child?

Is your child a boy or a girl?

In what city was your child born?

How old are you?

Do you have any other children?

How old are they?

What kind of work do you do?

What is your relationship with the child's mother?

What is your highest level of formal education?

[Although this questionnaire may seem long, what I'm aiming for is to get participants to tell me their stories. Main questions are left justified with follow-up prompts indented under the main questions. Although fathers may comment on their current relationships with their children, this is not the focus of this research project.]

Open Ended:

Please tell me about your experience of your child's birth.

What stands out the most from this experience?

Please tell me about your experience of finding out your child had been given a

Diagnosis of Down syndrome.

Did you find out pre-natal or post-natal?

Did your child have any other medical issues beyond the diagnosis of Down

syndrome?

Were you given any resources or support? Or, referrals for parent support groups?

Did you want resources? Were the resources helpful, updated and relevant?

Who delivered the news? When was the news delivered?

What was the manner in which the news was delivered?

What was it like interacting with members of the medical profession?

If you were not told directly by a medical professional what was your experience like when interacting with medical professionals (doctors, nurses etc...) after you found out?

If you were there upon receipt of the news, what did the medical professional tell you?

Did they deliver the news in a positive or negative manner? How did they tell you?

What was the affect of the Dr or nurse, etc...? Optimistic or pessimistic?

What stands out the most from this experience?

How did you feel?

How did you feel upon receipt of the news?

How did you feel days following?

What was the reaction of your partner?

What was the reaction of your family?

What feelings were evoked in you regarding their reactions?

What might you hope could have been different?

What would you suggest could be improved?