MARGINALIZATION AT THE MARGINS OF LIFE: PERCEPTIONS OF “UNHEALTHY” CHILDREN BEFORE BIRTH

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ABSTRACT

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Throughout history, those with physical and mental impairments have been deemed to be experiencing lives not worth living. The perception of their lives as not worth living has been shaped via numerous social channels. One significant means by which people gain insights and information about disabled people's lives concerns portrayals and knowledge asserted through forms of popular media. Especially in modern times, literature from the medical community offered to the public has often taken an authoritative tone, which has conveyed taken-for-granted assumptions about the quality of life of those with impairments. This information presented to the public about the lives of impaired people ultimately has the potential to shape significant decisions made by parents concerning whether to continue on with a pregnancy when the unborn fetus is reported to have a risk of a disability after birth. The main goal of this study was to analyze the meanings that are conveyed by the context of information presented concerning having a child with a risk of an impairment by those who claim medical authority.

The post-structuralist perspective was utilized in this dissertation research, directing attention to the often unquestioned assumption that to have an impairment is to live a life not worth living. In order to examine the potential impact of popular

literature from the medical community, I explored perceptions portrayed by medical professionals about the worthiness of disabled people's bodies and lives in pregnancy advice books. This study involved conducting an analysis of two different dimensions of the social discourse about this issue: the textual discourse in pregnancy guidebooks and an audience's perspective of the information offered in the guidebooks.

I utilized multiple qualitative methods in order to garner information about this topic. First, I performed a content analysis of the conversation of having a child with a potential disability in a small selection of best-selling pregnancy guidebooks. I followed with interviews with adult women of childbearing age to gain insight into how they interpreted information in the texts and constructed meaning about the desirability of having an impaired child. Specifically, I gained understanding about: *(1) Whether the meaning of the language used in pregnancy guidebooks provides positive, neutral, or negative connotations about having a disabled child; and (2) Whether the discourse of this information had an impact on the meanings potential future parents have about the desirability of having an impaired child.* This study illuminated the meanings conveyed and formed about a topic that is so often left unexamined in everyday life, yet has potentially life-altering ramifications for so many families.

For my brother Bradley, who is the happiest, most loving person I know.
You are a reminder to all, but especially me, that true happiness is not about
the bodies we live in, but the bonds we have with others who love us.
You have changed my life in the most profound and positive ways.

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TABLE OF CONTENTS

CHAPTER I

INTRODUCTION

Statement of the Problem

Pregnancy advice books and online forums available to expecting parents contain an abundance of information about seemingly every topic under the sun that might be relevant to parents, at any stage of their child's development. One specific topic discussed in these guidebooks concerns the topic of risks associated with having a child that is in jeopardy of being "unhealthy."[1] This is a central issue in pregnancy advice books about preconception care and pregnancy, especially. After all, the apparent goal of focusing on the highest level of health and precaution for an expecting mother before and during the time she is pregnant is to ensure the best "health" of a future child. In today's time, pregnancy and the notion of health risk in an unborn child are strongly associated with each other, as emphasized by Lee et al. (2010:299) when it is stated that,

> …the imperative at the individual level to become a risk manager weighs especially heavily when the message is communicated that the child is at risk. The drive to protect children 'at risk' and to increase the safety of children in general is, for these reasons, among the most powerful of contemporary cultural and policy norms.

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[1] The term "unhealthy" is used in reference to the meaning implied by pregnancy guides in reference to fetuses that have a condition or impairment. The specific term "healthy" is used in pregnancy guides to connote a fetus that does not have a condition or impairment, thus "unhealthy" is used in this dissertation as a contrasting term in reference to an unborn child with an impairment.

Whether the fear of health risks is initially self-imposed or comes primarily from outside social forces, it is clear that it becomes part of the experience of being pregnant for many women in the U.S. today. An expecting mother (or even a woman who may conceive a child in the near future) is taught and pressured to see pregnancy as a risky endeavor and to fear what the risk may result in, namely a child with an impairment.

Throughout history, children born with physical and mental impairments have been deemed to be experiencing lives not worth living (Proctor 1995; Pernick 1996). The perception of their lives as not worth living has been shaped via numerous social channels. One significant means by which people gain insights and information about disabled people's lives concerns portrayals and knowledge asserted through forms of popular media. Especially in modern times, literature from the medical community offered to the public often takes on an authoritative tone conveying taken-for-granted assumptions about the quality of life of those with impairments. This information presented to the public about the lives of impaired people has the potential to shape life and death decisions made by future parents concerning whether to continue on with a pregnancy when the unborn fetus is reported to have a risk of a disability after birth.

Discourse about the health of an unborn child in pregnancy advice books is a largely unexamined literature, even though it is something many encounter in their everyday lives. It is all too easy to take for granted the common assertion that having an "unhealthy," or disabled, child is something that is not desirable and should be avoided at all costs. Because there is a long history of taking a medical perspective[2] when discussing issues related to disability, it is not surprising that the phrase "healthy child" is equated with having a child without disabilities when discussing pregnancy and risks. However, this discussion helps illustrate a continued reliance on understanding disability and impairment as solely related to medicine and health problems. As evidenced in this project and in other research, much less of the discourse surrounding disability is focused on understanding the ways in which shared social understandings of disability potentially affect the lives of those who are disabled, as well as how they are perceived by family members and others. Specifically, social perceptions of disability often have much more profound and far-reaching effects on a disabled person's life than simply one's state of physical health as a result of having an impairment. While some impairments, such as Tay Sachs, make a fetus/infant not viable for life, other conditions do not inherently lower an infant's quality of life. If medical professionals make statements that are over-generalized and provide a negative connotation about having any child with an impairment, expecting parents may lack a more complex understanding of the quality of life of their child if it has some sort of condition.

One key reason it was so important to analyze pregnancy guide texts for this dissertation was due to the popularity and pervasiveness of advice provided to

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[2] Taking a medical perspective entails focusing only on an impaired person's physical limitations as the central factor limiting that person's life. This perspective will be discussed in detail later.

expecting parents. Pregnancy advice books are a key source of information about a multitude of topics related to pregnancy for millions of those who become pregnant. These guidebooks are aimed at women who are currently pregnant, with information about seemingly everything that can transpire from pre-conception through settling in at home after a child is brought home from the hospital. Expecting parents seek out information regarding pregnancy from a variety of sources, but consistently indicate that a primary source of knowledge is popular pregnancy advice books (Gardner 1995; Parrot and Condit 1996; Copelton 2006). The best-selling pregnancy guidebook *What to Expect When You're Expecting* (Murkoff and Mazel 2008)*,* alone, is reported to be the text chosen by 93% of women who read a book about pregnancy and has spent a total of at least 675 weeks on the New York Time's best-selling list (What to Expect 2015). Additionally, the author of this specific book has been deemed by Time Magazine to be "one of the 100 Most Influential People in the World" (What to Expect 2015).

Authors of pregnancy advice books like *What to Expect When You're Expecting* (Murkoff and Mazel 2008) and are in a position to provide information to millions of women (in the U.S. and around the world) related to their experiences with pregnancy and can help shape their understandings of this event. This opportunity for immense influence is especially likely given the increasing propensity since the early 20th century to medicalize and draw more concern to the events of pregnancy and childbirth (Abel and Browner 1998; Georges and Mitchell 2000; Armstrong 2003; Ehrenreich and English 2005; Conrad 2007). Seeing pregnancy as a medical concern/condition has helped drive the market for pregnancy guidebooks and has aided in the expansion of the authority given to those who provide information in such texts.

The expansion of power afforded to those who write pregnancy guides is indicated in many ways. One illustration of the authority conferred to these texts is demonstrated in the label bestowed upon *What to Expect When You're Expecting*, the "pregnancy bible," which relates it to something akin to a holy text for those looking for insights and information about a pregnancy (What to Expect 2015). One study that analyzed the reasons behind why women read pregnancy advice books also found that women appear to sometimes confer authority to the authors of the advice books because "… [they] believed overwhelmingly that information printed in books must be authoritative or it would not have been printed in the first place. [Pregnancy guidebooks] functioned as a constant pregnancy companion and women frequently turned to them both for advice and reassurance" (Copelton 2006:8). This study indicates that the advice books are a primary source of information for many women, often seen as more reliable, objective, and comprehensive than family, friends, or even medical professionals (Copelton 2006). Further, the authority of those who write these texts has extended through the development of additional parenting books for new parents, such as *What to Expect the First Year* (Murkoff and Mazel 2014) and *The Girlfriends' Guide to Toddlers* (Iovine 1999). The expansion of a claim of authority about parenting-related matters was not confined to pregnancy and the early years of parenting but, indeed, branched out even further into additional texts that provide information to those in the stage of preconception, as seen in *What to Expect Before You're Expecting* (Murkoff and Mazel 2009) and texts that encompass parenting information about a child's later years, evidenced in a book in-progress by Iovine, titled *The Girlfriends' Guide to Teenagers*. If expecting, new, or veteran parents do not feel they have enough information at their fingertips in these texts, these consumers can also access additional links to articles, columns, tweets, chat forums, and send e-mails via online websites established for the pregnancy guidebooks.

It is apparent that people encounter and use information from numerous popular media sources in living out their lives and in understanding what they experience. In searching out information from mass media outlets, it was necessary to remember that, "These sources are not just 'factual', they do not just provide representations of everyday life, but also provide one possible space within which for the expression of opinions and judgements" (Lee and Bristow 2012:508). However, questioning the factualness (or objectivity) of information from authoritative sources, about health-related issues, may or may not be a typical response from those consuming information from popular media. Few studies have explored the interpretation of information in pregnancy advice books by the audience that may read them, which was curious given the clear impact this advice has on parental decision making on a variety of issues related to pregnancy and child rearing. Thus, the goal of this dissertation was to explore the context of the advice and how the advice was understood and acted upon by parents.

Although there is a lot of information out there in popular media for new or expecting parents, research examining the level of authority enjoyed by these forms of media is relatively new and limited. Much recent research on this topic, instead, centers on scholars examining and debating who truly has authority within the relationship between a medical professional and a patient. Some researchers take the perspective that the person deemed to be a "professional" in these relationships claim and assert authority, and patients confer power to the professional (Parsons 1951; Copelton 2006; Lee, Macvarish, and Bristow 2010). A contrasting perspective that is more recent in health literature argues that patients exercise agency by using information provided by professionals to make decisions about their care in a more "patient-centered" approach (Copelton 2006; Alaszewski and Brown 2007; Markens, Browner, and Preloran 2010). This dissertation asserted that a combination of these perspectives may best explain what transpires when women use forms of popular media communications to gather information about pregnancy and childbirth. Specifically, I argued that medical professionals, and those who feel they are "experience-based experts"[3], assert authority by compiling the pregnancy advice books and publishing them. Many patients, or expecting parents, confer at least some authority to the professionals who write such books by purchasing them and consuming the information put forth in the advice books.

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[3] "Experience-based experts" refers to those who feel they have first-hand knowledge about a condition because they have experienced it themselves. Additionally, they feel that they can provide important "insider" information to others about the condition, though they lack credentials or formal medical training (Conrad and Stults 2010).

As noted previously, some women assume that what is written and published by "professionals" must warrant credibility and authority simply because it is been legitimated via publication (Copelton 2006). In the case of pregnancy advice books and the audience that reads them, there is certainly some level of authority that is asserted both by the professionals and from the audience, but less is known about the audience's interpretations of the information in the books after acquiring them. Although some women indicate that they initially perceived of the advice books as authoritative sources of information on pregnancy, less is known about the agency women may invoke in interpreting the information they encounter when reading the texts.

Purpose of Study

In this dissertation, I expanded on disability studies research in Sociology concerning the impact of social influences on the lives of disabled people. A topic that held much interest for me concerns the development and presentation of ideas and representations of disability. After attending a meeting of the American Sociological Association conference where the topic of pre-conception care[4] arose, I became interested in the notion of having a "healthy" child and the reasons behind the vast efforts so many people put into having a child that is considered healthy. I was interested in the connection that was made between having a "healthy" child and

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[4] "Preconception care" involves encouragement of all women of child-bearing age to take numerous steps to ensure having a "healthy" pregnancy and a "healthy" child, even before she is pregnant. This type of care relates to making healthy diet and lifestyle choices, among other factors.

wanting to have a child that is non-disabled. The implication of this discourse was significant because future parents often encounter medical discourse in pregnancy advice books that relays information laden with both overt and subtle meaning about whether it is desirable or not to continue on with a pregnancy when an unborn fetus is at risk for an impairment. Parents may then use this information to help inform them of decisions they might have to make about whether it is worth it to give birth to a child that may have a disability. Thus, decisions about whether to give birth to a child that may end up with an impairment was hanging in the balance depending on the context of information provided by medical professionals.

Examining information in pregnancy advice books utilizing content analysis was especially important because I was interested in studying the ways in which language and perspectives relayed about disability, presented about those perceived to have relevant expertise, might convey positive, negative, or more neutral connotations about a disabled child. It was important to pursue this type of research in order to illuminate the ways in which people in positions of power, who have authority to discuss and relay information about a topic such as disability, convey information about a group of people who have been marginalized in many ways throughout time. The ways in which people in positions of authority present knowledge and discuss topics related to those who are disabled, and how desirable and “normal” disability is, was important to investigate in order to understand processes of how ideas are transmitted about this population. The framing of a topic and the language used to discuss it can have implications for how this information feeds into the social construction of ideas about a topic by the audience who reads the information. Additionally, this study was important in that it shed light on one significant way in which medical "experts" assert knowledge about the topic of prenatal health of a fetus, which has not been the focus of much previous sociological research.

For this specific project, I began by analyzing information that is offered and targeted at women who are expecting a child in pregnancy guidebooks. Because many expecting parents rely on the advice of medical professionals and experience-based experts to help prepare for pregnancy and giving birth to a child, I examined how the topic of disability was framed in literature available to expecting mothers. In this research, I analyzed how the topic of having an impaired child was presented and *the ways in which* it is discussed. In my continued pursuit of gaining an understanding about how conceptualizations about disability develop and are perpetuated through discourse, I began my analysis by conducting a qualitative content analysis of a sample of texts most frequently read by expecting mothers.

In order to examine the potential impact of popular literature from the medical community, this study continued by investigating the often unexamined perceptions portrayed by medical professionals about the worthiness of disabled people's bodies and lives in pregnancy advice books. I was interested in the meanings conveyed through the specific terms and phrases used to describe "unhealthy" fetuses that are identified as having a certain level of risk associated with them. I argued that the symbolic meaning of the terms and context of the information about an unborn fetus that is at risk of an impairment conveyed a negative connotation. In approaching this study, then, I hypothesized that medical professionals who wrote these pregnancy guides relied upon (and continue the cycle) of viewing those with disabilities as “less than” able-bodied people, and as “at risk” for living incomplete, hollow lives. This first hypothesis related to the content of the discussion I examined during the content analysis portion of this study. I argued that to conceive of all disabled people’s lives as empty and “unworthy” lacks complexity and is based on a narrow-minded assumption, to say the least. I was critical of unquestioned assumptions, such as those made about the supposed inherently poor quality of life for those with impairments.

This research was an exploratory study of the information presented by medical professionals and other persons claiming to have authority concerning points about pregnancy and having a “healthy” child and how that information is interpreted by parents. I aimed to gain insight into the ways in which authors of these texts discussed information related to the topic of pregnancy, preconception care, and prenatal testing. I identified themes concerning the ways in which authors framed discussions of having a “healthy child,” along with perceptions about children who have some form of impairment. I conducted an analysis of a convenient, purposive sample of current, best-selling textbooks in order to investigate the discussion about the importance of having a child free of “defects.” This research aimed to elucidate the subjective nature of information and knowledge, even that which is offered by the medical community.

Significance of Study

Some previous studies highlight the importance of examining the context of information provided to patients from medical professionals. Researchers who study the interactions between expecting parents and genetic counselors find that although patients found counselors helpful, they report some problems with the counselors. Specifically, patients state that they receive little information from counselors about potential quality-of-life matters or positive and negative facets of parenting an impaired child (Roberts, Stough, and Parrish 2002). Other scholars note that doctors and others in medicine often provide misinformation to expecting parents about having a disabled child (Parens and Asch 1999). Researchers find that accuracy and depth of information provided by doctors and genetic counselors to parents directly affect the decisions of expecting parents in terms of whether they aborted an impaired fetus when a potential risk was identified in the unborn child. For example, in Parens and Asch's (1999) research, they conducted a social experiment with expecting parents. All of the expecting parents in both the control and experimental groups had received a previous genetic screening result that there was a specific percentage risk that their unborn child would have Down Syndrome. The control group was given the "standard" information from their doctors, typically involving details about the topic of risk and the choices the parents faced in regard to continuing on with the pregnancy or choosing to terminate it (i.e. have an abortion). In the control group, approximately 90% of expecting parents, given the information they received and regardless of their previously stated feelings about abortion, chose to terminate the pregnancy. Among expecting parents in the experimental group, who received more accurate and comprehensive information about having an impaired child (including a visit with a family where a child with Down Syndrome was present), approximately 90% of expecting parents chose to continue on with the pregnancy (Parens and Asch 1999). Therefore, research indicates that there is a clear connection between the information and knowledge offered by medical professionals and whether impaired children have the opportunity to live or whether they are aborted. However, this past research focuses on only one way in which expecting parents are potentially influenced by medical professionals via face-to-face interactions. Past research has not explored additional, specific means by which parents may be affected by those asserting authority over health issues like pregnancy via other types of mediums, such as through pregnancy guidebooks.

This dissertation research aimed to add to previous research by clarifying specific ways in which authoritative knowledge from those claiming to have some level of medical professionals may shape the perceptions of women of child-bearing age concerning having an impaired child. This study helped to fill in a gap by exploring written documents that have not been analyzed before in terms of how an author's points portrayed the specific topics of impairment, genetic defects, and the normalized version of what it means to have a "healthy" baby. Two key research questions asked and investigated in this dissertation research are: *(1) What language, phrasing, and overall context is assigned to discussion of the "risk" of having an "unhealthy" child in* *pregnancy advice books? and (2) What understandings and meanings do women assign to the language and context of information about the risk of having an unhealthy child in pregnancy advice books?*

This dissertation research was a follow-up study to Parens and Asch (1999) research. It was anticipated that there would be themes and patterns concerning the discussion of having an impaired child in these pregnancy guidebooks. The patterns present were perceived to be apparent in the specific language, terms, and phrases used to describe an unborn child that may be at risk for an impairment and will likely have a negative connotation. Additionally, I hypothesized that women who were part of the interview phase of this research were going to report that the information in the passages carried a negative tone concerning having a child with an impairment.

Because millions of people read these pregnancy guides and gain knowledge and insight about their unborn children, the information included in these books has the potential to have a significant impact on the ideas expecting parents have, or are forming, about various topics. Information from medical professionals may help to shape ideas about people with disabilities, specifically, by emphasizing their "defective" state and how undesirable they are to expecting parents. This issue, then, has life and death consequences for future fetuses/children and families if and when expecting parents are given news that their unborn child may have a risk of impairment and they make decisions about whether to continue on with a pregnancy or terminate it.

What has been missing from most research in the areas of family, health, and disability is the issue of how medical professionals, and others who establish authoritative knowledge about a subject, influence the audiences of that information. When this topic has been studied, attention has been given to only a few specific ways in which medical professionals have exerted authority about disability, such as by means of face-to-face interactions between doctors and patients (e.g. Parens and Asch 1999; Copelton 2006; Alaszewski and Brown 2007; Markens et al. 2010). Issues that play out in face-to-face interactions between those in medicine and impaired people (or their families) have been the main focus of past research in this area. This dissertation research, in contrast, intends to shed some light on ways in which specific groups (i.e. authors of pregnancy guides) assert authoritative knowledge about pregnancy through written documents. Doctors (specifically OBG-YNs) and women who have had children are specific groups of people who claim to have expert knowledge about pregnancy and convey this information in advice books about pregnancy. People do not construct meaning from interactions, alone, but do so also through interaction with various forms of media (i.e. written text) about a topic from someone who claims expertise. In line with the tenants of social constructionism, I assessed the ways in which understandings and meanings of impaired bodies are clearly socially situated.

CHAPTER II

LITERATURE REVIEW

Introduction

This dissertation research was concerned with understanding more about a specific way in which experts asserted authority over a specific subject area, namely how those claiming expertise about pregnancy discussed risks and having a healthy child in pregnancy guides. Scholars have studied the long history of the connections between medicine, health, and having an impairment. Additionally, past research has illuminated a number of ways in which cultural values and representations impact the ways in which people often perceive disabled people. A final area of research I outline in this chapter highlights the importance of our society's tendency to see disability as related to health and medicine, only, and to not see it as being socially constituted. Further, I clarify the significance of medical professionals having the authority to contribute to the construction of the idea that having a potentially impaired child is an undesirable state for expecting parents. This research project intended to add to research concerning family, medicine, and disability by illuminating that there may be clear ramifications for expecting parents and impaired fetuses due to authoritative knowledge from medical professionals.

Authoritative Knowledge

Authoritative knowledge is asserted by many different groups of people, about a variety of subjects. Further, authoritative knowledge is not simply given out, but audiences who receive the knowledge give power to those who create it by purchasing, consuming, using, and/or sharing the knowledge. Although there may be more than one type of authority on a subject and multiple knowledge claims, there is usually agreement as to who is given authority and which claims are the most valid (Jordan 1997; Copelton 2006). Those who purport having expert knowledge about health and medicine are an example of a group who produces and disseminates authoritative knowledge. Medical professionals are given credit as experts on matters related to birth defects and pregnancy because of a long history of medicalizing certain processes and states (Zola 1972; Conrad and Schneider 1992; Conrad 2007), such as disability (Goble 2003) and pregnancy (Jordan 1997). Scholars perceive this topic to be an important area of study because when medical experts assert authority over those with disabilities, for example, it appears to have a significant impact on perceptions and treatment of impaired people. This is clearly seen in research by Parens and Asch (1999), where they found that the information genetic counselors provided about the genetic risks associated with an unborn fetus to parents encouraged parents to abort their unborn fetus when there was an even small risk of impairment identified in the fetus. Examples like this of established knowledge from medical professionals helps indicate that the impact of this type of knowledge is far-reaching and can pose significant, potentially life and death, challenges for an unborn fetus with a risk of having an impaired body.

Influence of the medical profession

Medicine has been a social institution that has played a significant role in shaping conceptions of disabled bodies. Professionals in the field of medicine shape perceptions of impaired bodies through interactions with disabled people and by means of increased “surveillance” (Foucault 1994, 1995) and treatments for impaired bodies. Another particular way that the medical field has influenced perceptions of impairment concerns labeling impaired bodies as “abnormal” and treating them as such.

Medical professionals have frequently asserted notions of social Darwinism, or “survival of the fittest,” in response to impairments and how they should be treated. For example, impairments are often perceived to be mutations that are not “fit” or “normal” (Proctor 1995; Parens and Asch 2000; Kerr and Shakespeare 2002). As a result, historically, many medical professionals took part in the eugenics movement that flourished in the late 1800s and early 1900s that targeted impaired individuals (Proctor 1995; Pernick 1996; Parens and Asch 2000; Kerr and Shakespeare 2002; Kudlick 2003). Goble (2003:47) states that, “In Western societies…‘atypicalities’ have often been pathologized and result in negatively valued characteristics, such as intellectual, physical or sensory impairment.” Further, eugenics practices were likened to a moral imperative to find goodness and to free the world of any kind of human deficiency (Pernick 1996).

However, this connotation of abnormality or weakness is not innate among all of those who have an impairment. While some impairments do produce incompatibility with life and/or pain issues, many impairments do not, inherently, impose a lower quality of life. Many people in social institutions, in conjunction with much established medical knowledge, have produced social meaning concerning impairment. This is illustrated with the fact that there has been an assumption made by many medical professionals that impairment was inherently abnormal or a "disrupted state" (Proctor 1995; Parens and Asch 2000; Goble 2003). With so much inevitable genetic variation that occurs among humans, deciding what is "normal" is a highly subjective process, though medical judgements such as these have typically not been evaluated as subjective because they came from medical professionals.

Today, a new form of genetic cleansing has developed in the form of genetic and prenatal screening. These screening processes allow for the identification of undesirable bodies, but have come under a new name: prenatal screenings (Davis 1995; Cunningham-Burley and Boulton 2000; Kerr and Shakespeare 2000). Due to a rise in advanced medical technologies that can screen for potential genetic conditions, there is increased pressure for expecting parents (and even those who may be expecting in the future) to be "responsible" and try to prevent having an impaired child, at all costs (Pollitt 2003). To a large extent, people are equated with their genetic make-up and it is perceived that only the best genes should survive. U.S. society, and many other societies around the world, put a lot of faith in the "gold standard," objective nature of science and medicine that supposedly allows human beings to create the “perfect” human race (Becker 2000; Goble 2003; Pollitt 2003; Ekberg 2007; Weiss 2007). When a social constructionist lens has been applied to the practice of genetic and prenatal screening, however, it has become apparent that there is no way to be objective and value-free (see Parens and Asch 2000; Kerr and Shakespeare 2002; Taussig, Rapp, and Heath 2003). Social and cultural values of a specific time and place cannot be separated from the bodies that are valued. Indeed, legal policy was created in the past that relied on overtly subjective ideas about desirability of different bodies.

Laws put into effect concerning disabled individuals have covered a wide range of subject matter, from issues related to the violation of norms of aesthetic beauty to an impaired person’s right to life. Many of these laws have clear ties to the “truths” asserted by medical professionals concerning impairment and their recommendations for laws and policy concerning those with impairments. One profound example of the strong influence of the medical profession on legal discourse was visible in the laws of the early 1900s that advocated the eugenics movement and required “forced sterilization” for many people with impairments (Krotoski, Nosek, and Turk 1996; Rogers 1996; Thomas 1999; Parens and Asch 2000; Prilleltensky 2004). Further, women who were mentally impaired were especially likely to be targeted by this sterilization movement (Barnes and Mercer 2010). Social biases against disabled people reproducing because of a desire to prevent the reproduction of impaired bodies encouraged forced sterilization of disabled people. The indication that social biases are at work, and not objective genetic principles, is the fact that the majority of impairments disabled people have are not hereditary. In light of this information, policing the reproductive rights of disabled people is much less warranted (Prilleltensky 2004). The increased policing of bodies has been tied to eugenics practices because medical professionals have set stringent standards of the genetically ideal body, which has clear implications for the perception of those with any form of impairment.

Something else that is so often lost in the process of trying to perfect human genes is that "abnormalities" found in genes actually result in many variations, though people tend to conceive of them as solely negative. Those with visible physical differences, whether visible in a prenatal screening or in a living human body, have been singled out for abortion (Parens and Asch 2000), euthanasia (after an impaired infant was born) (Pernick 1996), or some other form of medical intervention because of medical professionals' emphasis on the impaired body as "the problem." The body is perceived to be the site of the "problem" and so it should be "fixed" in one way or another (Oliver 1990; Siebers 2001; Barnes, Oliver, and Barton 2002; Thomas 2002; Jaeger and Bowman 2005; Barnes and Mercer 2010). What has been lost in the emphasis on some bodies as being "abnormal," is that perceptions of "normal" genetic variation and "normal" bodies are not objective or value-free assessments.

Medical Model of Disability

Another way in which perceptions of impairment are established within the medical field is the inextricable link medical professionals make between disability and the body within the medical model of disability. In the field of medicine, it has been common to see disability occurring as a result of impaired individuals having “broken bodies” (Hughes 2002). Thus, medical professionals tend to downplay the vast role of social factors in disabling the physically impaired individual by emphasizing the medical model. The predominant view of disability throughout time, until about the 1970s, involved a medical model or perspective of disability that has placed undue emphasis on the impact of the physical experiences of disability at the expense of noting the social context. The medical model holds that an individual’s physical, physiological, or psychological impairment is the key to understanding the individual’s disability (Siebers 2001; Thomas 2002; Jaeger and Bowman 2005; Barnes and Mercer 2010; Mullner and Albrecht 2011). The medical model supports the claim that an impaired person needs only therapeutic rehabilitation and support in order to overcome the internal issues, and resulting limitations, the person experiences. It is argued with this model that this would allow impaired people to lead full, meaningful lives. When utilizing this model to assess the needs of people with impairments, it is posited that policies should address meeting rehabilitation, care-giving, and medical treatment needs so these individuals have aid in managing life with impairments (Barnes, Oliver, and Barton 2002; Barnes and

Mercer 2010). Additionally, this model supports the use of “experts” to define how people with impairments should attend to their “personal difficulties.”

One major disadvantage of this perspective is the lack of concern given to understanding the role social factors play in oppressing and disabling persons with impairments. An illustration of the emphasis on an individual’s impaired body can be seen by the fact that those in medicine promote efforts toward rehabilitation or a “cure” for an impairment, more so than recognizing that physical obstacles create the barriers that disable impaired people (Barnes, Mercer, and Shakespeare 1999). In order to draw attention to the social constructs that create disabling barriers for those with impairments, Sociology of Disability scholars worked to deemphasize physical limitations of the body and, instead, endeavor to highlight a social understanding of disability that “...makes it possible to see disability as the effect of an environment hostile to some bodies and not others, requiring advances in social justice rather than in medicine” (Siebers 2001:738).

Social Model of Disability

The social model of disability developed in the 1960s in conjunction with a strong emphasis on the advancement of human, civil, and political rights in the U.S., including those of disabled people (Turner 1993; Bryan 2006). The social model of disability overcame the main limitation of the medical model by contributing a critical awareness of the social influences shaping the lives of disabled people. However, no one model, theory, or perspective is perfect, nor can it account for all of the significant aspects of social life. What is important to note here, however, is that the social model opened up an entirely new focus within disability studies scholarship and in popular discourse. Finally, the social processes at work that help shape the lives of impaired and non-impaired people were visible and could no longer be taken for granted (Siebers 2001; Thomas 2007). Disability studies scholars have traced many ways in which social and cultural influences have shaped the negative social perceptions that have developed concerning disability over time. Many significant factors that have shaped and disseminated negative social understandings of disability over time clearly relate to cultural influences.

The Role of Cultural Values, Discourse, and Representation

There are numerous representations of various types of bodies that have been displayed to varying degrees throughout the history of time. Some bodies, however, have consistently been deemed to be desirable and others as less desirable (or even, to an extent, "repulsive") (Wendell 1996; Hughes 2002). Much emphasis is placed on a person's physical attributes and characteristics in U.S. society and these ideals help to determine certain types of bodies that everyone should strive to achieve. People are not simply pressured to judge their own bodies, but we are trained to assess other's bodies for "social cues," as well (Casper and Moore 2009). Further, some bodies are "hyper-visible," denoting more prestige and status to these types of bodies over others (Casper and Moore 2009), as is the case with idealized bodies appearing more often in all forms of popular culture. Impaired bodies, on the other hand, are often given the indication that they are perceived to have no appeal or value.

It is seen as socially desirable that a person have a “fit” body and one that the person has control over in every way (Wendell 1996; Barnes and Mercer 2010). The pressure to control one’s body is intrinsically tied to the cultural value of individuality in this society that emphasizes the need for mastery of one’s self and, if the ideal is not achieved, the individual person is solely to blame (Taussig et al. 2003). Bodies that “fail” are often set apart from those that “succeed” and the successful bodies are celebrated.

While idealized bodies are more prominent, other types of bodies that are less desirable are often hidden or “missing” from view, which conveys a lot about the disempowerment and lack of citizenship afforded to some groups of people (Casper and Moore 2009). On the subject of the amount and type of representation of impaired bodies, I extend that the portrayal of impaired bodies is more complex than may appear in a brief discussion provided by Casper and Moore (2009). Casper and Moore (2009) discuss how “hypervisibility,” which usually has a positive connotation as it emphasizes the propensity to frequently display only the most ideal bodies, can also occur in ways that highlight bodies perceived to be the opposite of “ideal.” Specifically, there is an increasing pattern of making bodies with genetic conditions “hyper visible” through prenatal screening as a means to identify and surveille them during pregnancy (Casper and Moore 2009). New technologies are making “risky” fetuses “hyper visible” in significant ways. With the ability to observe and police bodies through increased prenatal and genetic screening, impaired bodies are being exposed to a negative kind of "hypervisibility" (Casper and Moore 2009; Rothman 2010) that tends to impact these bodies in life-altering ways. Although there is, naturally, great variation in human bodies, there is a focus on the ways in which having specific characteristics makes a person more desirable and their appearance more "normal." Additionally, the "hypervisibility" of bodies perceived to be other than ideal has the potential to provide parents and medical professionals with increased opportunities to control which bodies continue on through pregnancy and which ones are seen as undesirable enough to abort.

Historically (and still today), impaired bodies have been portrayed in a specific kind of light. Representations of the disabled body indicate that it has been "...feared, repulsed, and repudiated" (Prilleltensky 2004). From Greek and Roman mythology to modern film and narrative, it is possible to view the history of disparaging, demeaning ways in which impaired bodies have been grotesquely displayed. Rosemarie Garland-Thomson (1996) has highlighted the numerous types of displays of impaired bodies as monstrous, as can be seen in the process of keeping dwarfs enslaved as jesters for royalty's amusement, as main attractions in circus acts, and as museum exhibits. Additionally, Wendell (1996) revealed that these bodies were adorned with additional costumes, cosmetics, and scenery in their presentation to emphasize their "Otherness." Susan Wendell's (1996:2) historical analyses provided illustration of the social constructionist perspective in that she emphasized the ways in which, "...the cultural resonances accorded [extraordinary bodily forms] arise from the historical and intellectual moments in which these bodies are embedded."

After a long history of displaying bodies as sources of entertainment in the public sphere, bodies also became spectacles in early medical laboratories and seminars. Thus, displays of unique kinds of bodies are constituted in numerous kinds of social contexts (Garland-Thomson 1996). The representations of impaired bodies do not convey essential characteristics about the bodies; as the history of displays of impaired bodies indicates, they are socially constructed and imbued with meaning.

Much like the images of impaired bodies that were represented as amusing "freaks," medical discourse and educational information about impaired bodies portrayed them in a similar fashion as abnormal. In the early 1900s, doctors and parents who interacted with impaired infants, along with the news media that reported on cases of these impaired infants, spoke of these children as "defective" and as "monsters" (Pernick 1996). Moreover, discourse about disability in classrooms and academia typically provides negative portrayals of disabled people through discussions presented in class and in textbooks, focused almost entirely on the medical needs of this population (Linton 1998; Thomas 2002; Jaeger and Bowman 2005). Discourse about disabled people can have a similar level of negative consequences for people with disabilities as stigmatization in interactions. The barrage of negative images and information about disabled people in society is a central factor shaping the stigmatization and stereotypes of people with impairments. Stigmatized perceptions of disabled people consistently interfere with the ability of a disabled person to participate fully in all realms of their everyday lives (Wendell 1996).

This study aimed to add to this previous literature that clearly indicates a negative slant when it comes to portraying impaired people and the ways in which it may be shaping the quality of life people with disabilities experience. This study contributes to sociological theory and, specifically, disability theory by providing confirmation of past literature that has highlighted ways in which disabled people experience marginalization due to a perceived inherent lack of ability to lead a quality life. Further, it speaks to the role of the audience, or patient, in interpreting medical discourse in light of the level of authority of the information provided by those deemed to be medical experts about a given subject. This research also suggests practical policy suggestions concerning the ways in which medical professionals, and those claiming medical expertise, discuss the topic of potentially having an impaired child and choices about continuing a pregnancy in such circumstances. This study provides useful direction for information and resources that could be added to the discourse available to expecting parents in light of suggestions provided by interview participants.

CHAPTER III

THEORETICAL ORIENTATIONS

Introduction

Although I took a grounded theory approach to analyzing the data gathered for this dissertation, I utilized theoretical perspectives to inform my understanding of perceptions of impaired people and how they are constructed, as well as to help in the development of my research protocol for investigating this important topic.

There is a long history of viewing disabled people as deviating from the norm and of labeling and oppressing disabled people because of those perceptions. Understandings of disability do not simply develop, though; ideas are socially constructed through a number of social channels. In this chapter, I outline the tenants of social constructionist and post-structuralist theory, which helped me to focus on a more fluid understanding of the meaning of having a disability. Namely, these theories remind scholars that the conceptualization of a trait is always socially and culturally situated. They hold that the characteristics people have do not carry inherent value or lead to pre-determined outcomes. A person with a disability, for example, does not have to be perceived in an inherently negative light and their quality of life does not have to be affected negatively because of a physical condition. While some conditions do, on average, produce some indications of poor quality of life, such as pain issues, other impairments do not produce negative outcomes, like pain. Thus, these theories help inform my understanding that disability is more complex and entails dynamic outcomes, rather than one simple pattern of negative life outcomes. These perspectives shaped all aspects of my approach to this study, then, because they directed me to explore information that is often taken-for-granted as objective and free of social and cultural influence.

Social Constructionist and Post-Structuralist Theories

Social constructionist theory provides significant insights about many sociological phenomena, including the social and cultural understandings of health and illness. What is taken for granted as reality is dissected so the socio-cultural foundations of what we see as essential “truths” are revealed. As articulated by Conrad and Barker (2010:S67), “Social constructionism is a conceptual framework that emphasizes the cultural and historical aspects of phenomena widely thought to be exclusively natural.” A social constructionist lens directs a scholar’s attention to the recognition that bodies do not possess essential meanings or characteristics; symbolic meanings and perceptions of bodies are socially conferred. The base of knowledge for social constructionism comes from a relatively new history of scholarship in the Sociology of Knowledge that garnered interest and major contributions beginning in the 1970s. This field brought attention to taken-for-granted assumptions about the nature of reality and knowledge claims in the social world (Freidson 1971; Berger and Luckmann 1971; Merton 2005). Included in this early scholarship were studies attending to unexamined notions of “health” and “illness” that are so prolific in this society. In order to comprehend the nature of social conceptions of health and illness, the influence of social and cultural factors on all aspects of the production of scientific knowledge had to be illuminated.

In relation to the development of concepts such as health and illness, social constructionist theory aims to critically examine knowledge claims from the field of medicine that purport to have found objective truth about some phenomenon. Social constructionism, also having ties to post-structuralist and postmodern theories, helps break down boundaries established by essentialist thinking to clarify the realistic fluctuations of states of being, such as being “healthy” or “ill” (Lupton 2003). In other words, what a society understand to be a “healthy” or “ill” state is not set in stone; the ideas attached to these concepts change over time, from place to place, and may be experienced and interpreted differently in interactions (Mannheim 1936/1970; Harding 1991; Webster 1991; Harding 1993; Burr 1995; Martin 1997; and Turner 2004).

A significant contribution of social constructionism, then, is that it allows sociologists to move beyond an unexamined notion of the ways in which a person understands their health based on social understanding. Instead, the researcher is better able to conceptualize information about bodies, health, and illness as influenced by outside factors and not as entities that have essential characteristics, but as ones laden with social meaning. The consequence of continuing on with the routine actions and thoughts of everyday life without disrupting them leaves the world and, most importantly, the social context of everything a person does, unexamined (Berger and Luckmann 1971). Remaining uncritical of the taken-for-granted assumptions that have been socially constructed about disabled people is a dangerous proposition. It is dangerous because it may lead to parents making the decision to not continue on with a pregnancy where an unborn child is at risk of an impairment due to over-generalized notions about a poor quality of life for all impaired people.

Taking a social constructionist stance leads me to ask the question: what constitutes “normality”? If the measure of what is “normal” in the modern, post-industrial world is based on superficial, materialistic achievements, then disabled people likely will not have nearly as much opportunity to achieve “normality.” However, if “normality” is defined as perceiving one’s life to be enjoyable, meaningful, and fulfilled, then most disabled people would be considered to be absolutely “normal” (Wendell 1996; Hunt 1998). The process of determining what is normal, based on what is perceived as desirable, is of consequence when assessing the quality of future children’s lives.

Labeling and Deviancy

One reason people with disabilities are stigmatized and oppressed is due to the presence of a perceived limitation or lack of normalcy. Impaired people have been labeled inadequate and deviant because their biological, anatomical, and/or mental state has been socially perceived to be a sign of deficiency (Barnes and Mercer 2003). For centuries, those in positions of power, such as those in the medical establishment, have had control over defining and labeling impaired people (Nagler 1993). Thus, these same medical professionals, and many others in numerous social organizations, have helped determine the social perception, and thus the social reaction, to disabled people.

Light has also been shed on the significance of doctors having the power to label some bodily states as “normal” and “abnormal.” That which was defined as “sickness” or “illness” was branded as, inherently, deviant because it disrupted the flow of social contributions from some members of the society (Parsons 1951; Freidson 1988). Adopting the stance that ill individuals who cannot fully contribute as much to social activities as others may begin a slippery slope.

One main concern with this process is that what becomes defined as “sickness” is subjective, based on the social and cultural understandings prevailing at a distinct point in time (Lorber and Moore 2002; Joralemon 2006). What is perceived to be “normal” or “abnormal” is always changing because it reflects cultural and moral values, which are always under transformation (Starr 1982; Brown 1995; Lorber and Moore 2002; Turner 2004). A key concern with this process is that ill people are perceived as less valuable to a society because of the disruption in productivity brought on by the condition they have. Important questions must then be asked: What is the foundation for deciding how much productivity a person must achieve in order to be “useful”? Also, what is the objective basis of having one group of professionals in a position where they decide which conditions are “valid” and which ones fall outside the realm of “normal”? There are social processes at work behind identifying what is “normal” or “abnormal” (Becker 1963) and social constructionist theory advocates examining these processes.

Whenever society deals with issues of normality, it is imperative to examine the often unquestioned role of social influences clouding the ability of anyone, including medical professionals, to be objective. As discussed previously, there is no special training medical professionals receive that could allow them to become completely objective and to interpret situations and conditions in a socially un-situated manner. Even though our society tends to perceive scientists as value-free and as embodying the ability to convey “truths” about everyday life to the masses (Webster 1991; Arksey 1998), it is imperative that society not lose sight of scientists as subjective human beings (Sassower 1993; Brown 1995). To be clear, whether an issue is, in fact, a disease or not is not the topic of contention among social constructionists. Instead, the concern focuses on the *social development and implications* of defining a mental or physical condition as a “problem” in need of medical attention (Lupton 2003; Conrad 2007; Conrad and Barker 2010). The application of demeaning labels given to those with impairments has perpetuated destructive, stereotypical notions about disability. In *Claiming Disability,* author Simi Linton (1998:11) articulates that: “… the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy.” The process of negatively labeling a group of people is indicative of classifying the persons within the group as abnormal. This labeling process applied to disabled people often occurs without regard to what specific impairment a person has or how the person’s quality of life is impacted.

In addressing how a group comes to be viewed as socially deviant, Howard Becker (1963:8) writes that,

> *social groups create deviance by making the rules whose infraction constitutes deviance*, and by applying those rules to particular people and labeling them as outsiders. From this point of view, deviance is *not* a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an 'offender'. The deviant is one to whom the label has successfully been applied. [Emphasis in original]

Becker's argument delineates a foundation for understanding social oppression as the result of the social reaction to a person's alleged abnormal, biological characteristics. Socially constructed labels applied to impaired people are often due to ideals created by people in positions of power and reinforced by means of social control. This directs me to investigate the ways in which publications written by medical professionals may help to maintain already existing negative labels for disability or create new labels. The discussion of disability in these publications has the potential to do more to solidify the negative labels that already exist about disability than to simply provide helpful or value-neutral information to expectant parents who may need make decisions about having a future child.

Knowledge, Power, and Meaning

Understanding the connection between knowledge and the power that is behind the production of ideas is essential in order to comprehend the social meanings of, and reactions to, disability. In her paper *Disability Theory: Key Ideas, Issues and Thinkers*, Thomas (2002:49) states that "…all social phenomena, including disability and impairment, should be understood to be woven through, and out of, cultural ideas and discursive practices: there is no 'reality' independent of ideas concerning it." Further, social constructionists and those who take a post-structural view emphasize the connection between powerful structural influences in society and the development of social responses to ourselves and others (see Foucault 1972; Burr 1995). As stated by Cherryholmes (1988:35) in his book *Power and Criticism: Poststructural Investigations in Education*:

> Discourses are generated and governed by rules and power… [They are a product] of history, culture, politics, economics, and language. Individuals are linked to macrosocial processes and institutions when they become socialized, and by this mechanism power helps shape how we think of ourselves and act.

Notions about disability are presented to various social audiences via a number of channels. One example would include sources of media such as television, magazines, and newspapers, which may present information about disability to a wide variety of audiences, though they do not usually portray disability in a positive way (Jaeger and Bowman 2005:ix). Another example of how portrayals of those with disabilities are conveyed to social audiences would include information provided in books, such as pregnancy guidebooks for expecting parents. This dissertation research was designed to gain insight into how medical professionals produce discourse about disability using the power and authority they assume about pregnancy and health risks for unborn children.

Much like scientific fields, in general, the field of medicine (and all the knowledge it produces) is often over-looked as a site of fruitful critical analysis because people tend to have faith that science informs them of “truths” about everyday phenomena (Webster 1991; Lorber and Moore 2002). The factors influencing the social production of medical knowledge is often a taken-for-granted process. Additionally, because medicine is where people tend to experience the most interaction with science, medical professionals are typically afforded credit as being objective and value-free in their interpretations and assessments (Arksey 1998). Medicine is different from other types of professions, in that its knowledge is deemed powerful and absolute. Indeed, sociologists did not even analyze medicine or medical knowledge, at first, because of its almost “untouchable” nature as a field of objective truths (Arksey 1998; Lupton 2003).The medical profession has been elevated to a level of privilege and authority that inclines people to believe most of its knowledge claims in a way similar to believing in religion (Starr 1982; Freidson 1988; Webster 1991; Jordan 1992).

Having the authority to dictate the perceptions and understandings of a central aspect of human life allows a profession to gain an immense amount of power over other’s lives. Starr (1982:9) emphasizes that, authority, after all, “...signifies the possession of some status, quality, or claim that compels trust or obedience. It calls for voluntary obedience, but holds in reserve powers to enforce it.” The field of medicine purports that its main purpose is to utilize scientific principles as a means to control "disease" (Parsons 1951). However, in order to control disease, medicine must have the power to exert control over people's bodies because this is where disease resides. Arguably, power is often not a salient entity and it is often at work in hidden processes, operating at many different levels of the social structure (Lupton 2003). Social constructionism invites critical analysis of these often over-looked aspects of the use of power.

Power can present itself in numerous ways, by means of asserting a knowledge claim as the ultimate "truth" about an issue at hand, as a suggestion for treatment for an ailment, or through acceptance or resistance of a medical dictate. However, power is not embodied in a material sense as a *thing*; it is an integral part of interactions between groups of people where one is dependent upon the other as a source of authoritative knowledge (Fleck 1979; Starr 1982; Elias 2005). Foucault (1994, 1995) illuminates authoritative knowledge in the context of medicine as present in interactions and prescriptions for treatment between doctors and patients. Because doctors have persuasively influenced the lay public to view medicine as the ultimate authority concerning health and illness, patients all too often subject their own bodies to the "clinical gaze" of medicine (Foucault 1994). This gaze allows medical professionals the license to exercise control over patient's bodies via an initial examination and a routine of steady surveillance in the form of tests, medical consultation, and treatment. Thus, not only is "surveillance" (Foucault 1994, 1995) present in the form of actual, physical interactions, but it carries over into self-surveillance in the form of executing physical and drug therapy regimens, special diets, and exercise programs dictated by medical professionals. Power to control other's perceptions of what is a health concern, what they should do in response to the condition, etc. is able to be employed because medical professionals have been granted the authority to do so (Burr 1995).

Some social scientists have asserted that lay citizens are completely dependent on medical professionals for understandings of health and illness because the public perceives professionals to provide objective information (Starr 1982). In contrast, many scholars (see Arksey 1998; Collins and Evans 2002; Conrad and Barker 2010) argue that it is imperative to recognize the complexity of the perceptions people hold about their experiences with health and illness. Social constructionist theory helps us accomplish this task by directing attention to the ways in which people both have the capacity to negotiate and resist authoritative judgments and interpretations of their health experiences. As articulated by Lorber and Moore (2002:7), "The definition of what constitutes illness is often embattled terrain." Although physicians may have a significant impact on which conditions become medicalized, influences from other directions impact the progression of the medicalization process.

There are numerous ways in which knowledge is produced, affirmed, transformed, resisted, and denied in interactions between patients and medical professionals. The outside social world does not have a disconnected power to defer judgments about status and identity; people engage in the formation of the world around them through everyday interactions and, thus, help to shape understandings in the social world (Blumer 1969). Patients are agential in resisting the diagnoses/ treatment plans medical professionals develop. This perspective directed me to examine the ways in which the audience, the intended target of the pregnancy guides analyzed in this study, engages with the information they are presented in the guides and whether they accept and/or challenge the knowledge.

CHAPTER IV

METHODOLOGY

Introduction

The main focus of this dissertation research was centered around the ways in which having a potentially impaired fetus/child was constructed and conveyed in pregnancy advice books. Due to this focus, employing a qualitative content analysis was most fitting in order to examine the content and underlying meaning of the discourse and language utilized by the authors of the texts (Creswell 1999). However, because text does not have apparent meaning outside of an audience who encounters the information and develops meaning about it, a small collection of interpretations of meanings about the data was also useful to this research endeavor. Thus, in addition to a content analysis of data found in pregnancy advice books, I conducted qualitative interviews with a sample audience of those who are most likely to read these texts. I did this in an attempt to gain insight into the symbolic meanings others impose upon information found in the pregnancy guides, which gave additional perspective beyond the interpretation of the researcher collecting data. Numerous scholars discuss the need to use multiple methods of inquiry in conducting research (e.g. Maxwell 1998). Due to the value of obtaining information from multiple sources, I utilized two qualitative methodologies in order to maximize the amount of insight gained from multiple sources and to reduce limitations that may accompany each individual type of methodology. Also, I employed more than one methodology in an attempt to gain more insight into the ways in which multiple groups of people (such as professionals and audiences) helped shape knowledge and perceptions concerning having an impaired, or “unhealthy,” child.

Using multiple methods in scientific research allows for more holistic “symbolic realities” to be understood (Berg 2004). On the benefits of utilizing multiple methods, Berg (2004:5) asserted that,

> Each method, thus, reveals slightly different facets of the same symbolic reality. Every method is a different line of sight directed toward the same point, observing social and symbolic reality. By combining several lines of sight, researchers obtain a better, more substantive picture of reality; a richer, more complete array of symbols and theoretical concepts; and a means of verifying many of these elements.

The aim of this dissertation, then, was to investigate the social construction of the topic of potentially having an impaired fetus/child from different lenses, both from the perspective of authors of pregnancy guide texts and also through the meanings associated with the text by those who may read the advice books. It was useful to use multiple methods in order to identify if the data one collected using one method could be confirmed or contradicted by data from another method and source. Utilizing multiple methods can serve as a test of the validity of the research (Berg 2004). Using more than one method helped me understand how different sources of information, from those in different social positions, shaped the discourse and meaning associated with the social phenomenon being studied.

In conducting a study focused on the social constructions of having a child with an impairment in pregnancy guide books, it was necessary to outline some of the specific ways in which critical theories encouraged a critical examination of these social texts. Theory helped guide my research in regard to forming the broad research questions investigated and the research design employed. I utilized several theoretical perspectives that helped influence a number of aspects of this study. My theoretical orientations helped direct my topic of study, what methodologies were essential to use, the questions asked, how I analyzed the data collected, and many other features of this study. Examining the construction and dissemination of knowledge via written text, for example, relates to the tenants of taking a critical perspective within social constructionist and post-structuralist theories. These theories emphasize analysis of taken-for-granted assertions of knowledge and the context of that information (Berger and Luckmann 1971; Freidson 1971; Merton 2005). Specifically, these theoretical perspectives encouraged me to investigate and elucidate the subjective nature of concepts and terms used in conjunction with a given topic. An illustration of how this impacted my study is exemplified in the core goal of this research: to assess the terms used in pregnancy texts when describing the potential outcome of having a child with an impairment and the subjective meaning of this language. The social constructionist and post-structuralist theories, then, supported the analysis of terms like “unhealthy,” “healthy,” “defective,” “risky,” and “abnormal” that are often paired with discussion of impairment, which is an example of taken-for-granted associations that often go unquestioned.

By conducting the content analysis, I gained a sense of the ways in which those deemed to have medical expertise shaped the discourse of birth defects, fetal health, etc. for a large number of women. This analysis allowed me to look at already-recorded discussions, per se, of the topic I studied, as it is discussed by people who are afforded positions of power and authority on the subject. In order to help facilitate a deeper understanding of the meanings that may connect with the discussion of potentially having an impaired child in the pregnancy texts, though, I used a second methodology. Interviews were completed as a second means to gather insight and to serve as a "check" of the initial analysis of the information. As the research for my dissertation was exploratory in nature, I used methodologies that yielded rich qualitative data that identified language and discourse patterns by different groups of people. Specifically, I used interviews in conjunction with the textual analysis in order to explore discussions of potential impairments in unborn fetuses. During the interviews, I selected short excerpts from the pregnancy guidebooks analyzed during the first phase of data collection and I asked women who are likely to encounter these guidebooks questions about their perceptions and interpretations of the information.

This chapter highlights, in detail, the process of data collection and analysis for both types of research approaches utilized. The outline I provide delineates how the sample of texts was chosen and interview participants were recruited, the phases of coding textual and transcribed data, and other specific features of the data analysis process.

Content Analysis

For the first phase of my research, I conducted a content analysis. This analysis focused on a small sample of books related to pregnancy, argued by many to be information that expecting parents should be aware of prior to, and just after, the birth of their child. A sample of three pregnancy books that are considered by several national bookstores to be "best-selling" were selected for analysis. Looking at this sample provided a valuable starting point for gaining insight into the ways in which information about the potential of having a disabled child is presented to expecting parents.

Sample

In order to choose a sample of pregnancy guide books that would be relevant for inclusion in this study, I located lists of best-selling pregnancy advice books. I determined the status of the top "best-selling" by looking at different national bookstore best-seller lists on the Internet for books on the topic of study. I obtained a list of best-selling pregnancy guides from top online bookstores, including Amazon.com, Barnesandnobles.com, and Allbookstores.com. Although these websites did not intend to represent all top national bookstores, the same or very similar books were consistently found on the best-selling 10 pregnancy guide books among a multitude of different online book-seller sites.

For the specific sample of books in this study, I selected books that were consistently listed in the top 10 pregnancy books, were at the top of the lists, and were aimed at general audiences (such as books not directed at a specific racial, ethnic, or religious group). To find the top best-selling books on these bookstore websites, I typed “pregnancy books” into the search engine and selected the sorting option “bestsellers.” For Allbookstores.com, I searched “best-selling” books first, then selected the “Women’s Health” grouping. The books I selected for inclusion in this research included: *What to Expect When You’re Expecting* by Heidi Murkoff and Sharon Mazel (2008)*, The The Girlfriends’ Guide to Pregnancy* by Vicki Iovine (2007), and *Mayo Clinic Guide to a Healthy Pregnancy* by Roger Harms and Mayra Wick (2011). Although the only criteria for inclusion of books in this study included consistent appearance on pregnancy guide best-seller and not being directed at a specific audience, the texts selected for the content analysis portion of this study contained particular characteristics. These books included a variety of approaches and types of authors that ranged in terms of traits of the authors. Namely, the authors of the texts chosen for inclusion exert authority about pregnancy from different standpoints, such as some authors being medical professionals (see Harms and Wick 2011), mothers who have had children and have consulted heavily with medical professionals (see Murkoff and Mazel 2008), and mothers who have simply had experience giving birth and want to share their experiences with other women (see

Iovine 2007). All of these authors claimed to have at least some level of medical authority about pregnancy in their pregnancy guidebooks. In some texts, such as *The The Girlfriends’ Guide to Pregnancy* (Iovine 2007), there is a combination of people who contribute to the authoritative information, including the main author who has had multiple children, along with an OB-GYN. In this text, the OB-GYN, in a sense, consults in the writing process about certain sections of the book considered more “medical,” such as when the author outlines genetic screening tests. The approach, or tone of the books, varied from more professional (e.g. Harms and Wick 2011) to informal, as if the author was talking with her “girlfriend” in a more personal tone (e.g. Iovine 2007).

After choosing the sample of texts for this project, I reviewed the table of contents and index sections for each book to identify possible areas where information about disability might be more centrally located. After reading all of these sections and skimming over some additional sections, it was apparent that all of the discussions of risk and having a “healthy” child would pervade much of the pregnancy books and were not just located in a few chapters or sections. Therefore, I chose to include every page in the books in the sample for this study as ones that would be read and examined. However, I still paid particular attention to sections and chapters addressing pre-conception care, genetic and prenatal testing, risks during pregnancy, and complications during pregnancy. As I read over these texts, I identified keywords signifying a discussion of disability, impairment, and defects and created a comprehensive list of terms used by authors. A list of these key words are presented in Appendix A.

Data coding and analysis

The aim of this study centered on gaining an understanding of how authors used language to frame the topic of birth defects, impairment, disability, and the hope of having a “healthy” child (or a child free of impairments). I identified sections and sentences in the pregnancy texts that related to these topics by locating keywords associated with potentially have an impaired child. After reading the texts and recording all of the data that related to the topic of potentially having an impaired fetus, I created a coding system for the themes reflected in the text. As is traditional with exploratory qualitative research studies, I inductively created the conceptualization for the different themes present in the texts, grounded in the data obtained. Data collection and data analysis were not seen as discreet and separate phases of qualitative inquiry, but occurred simultaneously (Taylor and Bogdan 1998). The initial construction of categories of data began with the data collection process, as the data was initially encountered and meaning emerged. In the assessment of the manifest content of the data, I identified a keyword (or keywords) that characterized the general idea each piece of data conveyed. For example, if a sentence discussed the need for pregnant women to avoid drinking alcohol because of an increased risk of a problem for the unborn fetus, I noted “increased risk” and “problem for the unborn fetus” as indicators of the topics that related to the health of the unborn child. This allowed for a manifest content analysis of the text in order to identify initial themes or topics present. In further phases where the data was reread, I employed latent content analysis in order to analyze the context that the text appeared in, specifically the location of the text in terms of chapter title, subheading, and other text in the same paragraph and on the page. In these stages, I reread the data multiple times (on different occasions) and I recorded notes about the deeper meaning and context of each piece of data. This more in-depth analysis of the text allowed me to identify contextual meanings and assertions of the information present (Berg, 2004).

Themes

In order to obtain an initial list of themes for each piece of text, I used an open coding format, where I identified a general theme or topic referenced by the text. The initial theme was often indicated by the specific language and terms noted in previous rounds of analysis. From the initial list of themes I recorded for each page containing text related to disability, I noted themes and topics that might have been found listed together, such as *risk* being present when “risk,” “risky”, “precaution,” “potential harm,” or “likelihood” are discussed in the same section of text (Berg 2004). From these groupings of commonly associated terms in my analysis, I identified some main categories that represented the themes of the pieces of data. I established these main analytic categories after reviewing all of the initial themes and meaning-laden contexts of each piece of data examined.

This type of coding process was used, in part, because coding in this way (allowing for the prominent themes and categories to be grounded in the data rather than determined ahead of time) was beneficial in that it was difficult to try to establish categories for information found in texts before I read the texts. It was more useful to allow patterns and themes to emerge from the data that illustrated patterns that I could ascertain.

After completing the content analysis phase of this dissertation, I selected key illustrations of the themes found in the pregnancy guidebooks that represented two of the prominent themes found during the content analysis. These selections were used in the second phase of the study when interviews were completed with women who could encounter these guidebooks as a potential audience of the texts. The interview participants were asked about their own interpretations and meanings associated with the excerpts selected from the content analysis.

Interviews

The second phase of this dissertation was also qualitative and involved interviews as a means of gaining more insight from those that could likely be an audience for the guidebooks analyzed in the first phase of this study. Interviews were especially useful in in order to gain an understanding about the ways in which different groups of people play a part in constructing the perceptions and understandings an audience has concerning the potential of impairment in an unborn child. Specifically, potential future mothers who could encounter pregnancy guidebooks were asked about their perception of the information provided in the advice books.

Additionally, another key purpose of the interviews with a potential audience of these guidebooks was to provide a check on the validity of the themes identified in the content analysis phase of this research. Interviews, then, allowed for the opportunity to gain information using a different methodology that provided "… a different line of sight directed toward the same point, observing social and symbolic reality" (Berg 2004:5).

In early 2015, I submitted an application for IRB approval and was granted permission to progress with the study (IRB approval #i047823). After obtaining permission from the IRB, I conducted interviews with 15 women who could potentially become part of the large target audience of the pregnancy guidebooks analyzed in the content analysis phase of this dissertation research. Data collection began on August 3, 2015 and concluded on November 13, 2015. The interviews involved structured questions that were open-ended, allowing participants to provide detailed responses using their own language and constructed ideas about the topics discussed. The full list of questions asked during interviews is included in Appendix D. Interviews were held at a variety of settings, which were determined by each participant, based on what was convenient to them and/or preferred for another reason. Meetings for interviews took place in a variety of public settings, with some over-lap between participants. Some locations included: the Grand Valley State University (GVSU) Pew downtown campus (at the student center, a quite study area, or outside in a courtyard on the campus); the GVSU Allendale campus (at the main library, at my office, or a study area); and also at the Grand Rapids downtown public library.

Each interview lasted from approximately 12 to 19 minutes and they were tape-recorded with the participants' permission. The interviews were transcribed by an outside party (a previous student I taught at GVSU who has her Bachelor's degree in Sociology and who went through training for transcription work). Transcription of the interviews took place shortly after each one was complete. The typed transcriptions were then reviewed by myself, where I listened to each interview and double-checked the transcriber's work.

As another means to gather and provide supplemental information about the feelings and perceptions of the participants in the study, I recorded detailed field notes during and immediately after each interview. Specific details were also noted about the location of the interviews (including sights, sounds, where we sat, etc.); the gestures, body position, and body movements of the participants that communicated non-verbal indications of feelings and comfort; and my own feelings about the interactions within the interviews. These additional details offered important contextual information that I could later recall/revisit concerning a participant's mood, display(s) of emotion, and interaction details within the setting.

The interviews started with introductions and information on my part about who I was as a student and researcher, some brief general comments about what the interviews would entail, and some informal conversation about how the participant came to see information about my study (i.e. where did they see a flier, why were they interested in participating, etc.). This first phase of the interview was not only about gaining some insight about the participant and letting participants know some bits of information about myself, but also to help build rapport so we could feel more comfortable talking with each other. After this initial phase of chatting, I presented the informed consent form (see Appendix C) to the participant, giving them one copy to take with them and one to read over and sign so I could retain it for my records. After reading over the first page of the form, which outlined the study and what they would be asked to discuss, I asked each participant if they still felt comfortable taking part in the interview. I did this as a means of double-checking that they were alright with discussing the topic at hand and didn't have any particular sensitivities to the topics that would be discussed. All women readily indicated they were happy to participate and signed the form. I reiterated to each participant that they could skip any question they didn't feel comfortable answering, they could stop the interview at any time, and could ask questions about anything that was confusing as we progressed. I gave them the small monetary amount of $10 and emphasized that this was a small token of appreciation for *any* participation in the interview and for whatever assistance they could provide in completing however much of the interview they were comfortable with completing.

As another means to ease into the interview, I outlined each step of the interview and the types of questions I was going to ask them for each section of the study for each participant. Each interviewee indicated they were fine with the structure of the interview and I then asked if it was acceptable to turn on the tape-recorder so that I could be sure to get all of their points down accurately for use later when analyzing the interview. They each mentioned that would be fine (in addition to having already indicated that they were amenable to the interviews being tape-recorded on the consent form). From that point, the interview proceeded through questions about demographic and background information first, and then initial assessment questions next concerning their initial thoughts about how they might feel if a doctor told them they were pregnant with a “healthy” child versus a child with a “chance or risk” of having a child with a disability.

The last set of questions pertained to their perceptions of passages of information I provided them that had been drawn directly from the pregnancy guidebooks I analyzed in the first phase of this study. For this last section of the interview, I had participants read over a short passage of information from one of the pregnancy guidebooks (see Appendix D) where the authors discuss potentially having a child with an impairment. I then asked participants a series of questions that attempted to obtain insights about their perceptions of the information (such as whether they felt the information had a more positive, neutral, or negative tone when discussing disability) (see Appendix D). I also asked respondents to discuss the meanings conveyed in the specific language used in the passage in an attempt to get at what terms led them to feel a passage was more positive, neutral, or negative. After reading two different passages and answering questions about their perceptions of each passage separately, I gave them another final opportunity to add any comments or insights they wanted to share about the passages they had just read. After the interview was completed and the tape-recorder was turned off, I discussed a bit more with participants about the role their interviews and insights played in my overall research project. I thanked them again for their help and their willingness to help provide reflections about the topic at hand. All participants seemed interested in the larger context of the research and many indicated they were more than happy to help with what they felt was a worthwhile and important study. These comments were helpful to me, as they helped affirm that participants seemed at ease with their participation and did not appear upset or uncomfortable with the topic they had been discussing during the interview.

Sample

Because the most likely target for the pregnancy guidebooks analyzed in the initial phase of this study included women of child-bearing age, this was the general population recruited to be participants in interviews. There was a wide range of guidebooks related to pregnancy and parenting aimed at different populations. There were books targeted at pregnant women, some developed expressly for partners (specifically males) of pregnant women, others for women who are not yet pregnant but are planning to become pregnant in years to come, and many other books aimed at special populations for which the books were developed. The pregnancy guidebooks analyzed in the content analysis phase of this research were the books aimed, primarily, at the broad, general population of women who could become pregnant in the near future or are currently pregnant. These books are, specifically, aimed at women of child-bearing age. The books are not written for, marketed at those who are partners to women who are pregnant. Given the target audience for these pregnancy advice books, I focused on asking adult women of child-bearing age about the meanings they have for select sections of information in these pregnancy books.

In total, 15 adult women (over the age of 18) of child-bearing age took part in this study. As this was an exploratory study and because obtaining a representative sample for this study was not a key concern, the aim in recruiting participants was to locate a convenience sample of adult women. Recruitment of participants initially consisted of posting fliers (see Appendix B) in public places where a lot of people visit, including on enclosures at public bus/transit sites and on bulletin boards at public libraries. The fliers provided some basic information about the study, including who could take part in the study (adult women, over the age of 18, not currently pregnant), the general topic of the study (to gain an understanding about the participant's perceptions of disabled people), and contact information so they could ask questions or schedule a time to meet.

Although my aim was not centered on trying to find a representative sample of women, public spaces such as bus stops and public libraries in Grand Rapids are often used by people who occupy a diverse array of social statuses in regard to social class, race, etc. It soon became apparent, however, that these sites either directly prohibited the posting of fliers or were, for unknown reasons, taken down very quickly by unknown people. I did attempt to slightly modify where fliers were posted by putting up fliers on telephone poles directly outside of the public libraries (and on sidewalks right out front and on the side of the library buildings). However, I found that fliers I had posted in other areas of town were working more successfully to appeal to potential participants for this study. The only locations among the aforementioned public spaces, where fliers were allowed to be posted and remained for a longer period of time (i.e. for multiple days), were the bus enclosures near or on GVSU's Allendale or Pew campuses. Upon posting the fliers in these locations, not only did the fliers remain posted for a longer period of time, but women interested in participating in the study immediately began contacting me to set up times for interviews. Indeed, most interviewees who took part in this study contacted me after seeing a flier posted on or near GVSU's campuses. Only one participant from the study contacted me after seeing a flier posted near a bus enclosure in downtown Grand Rapids (not at the downtown GVSU Pew campus).

In addition to posting fliers in public places to recruit adult women for this study, another unexpected opportunity for recruitment occurred shortly after completing my first interview. Snowball sampling was used to find additional people to complete interviews when the initial participant that took part in an interview, during our informal conversation before the interview actually began, asked if she could help with my study by posting fliers in her apartment complex and letting some of her friends know about my research. I indicated that would be fine and that I appreciated her willingness to offer help. A downside to snowball sampling that often emerges is that a study may become laden with participants who have similar characteristics (Berg 2004). However, the women who participated due to snowball sampling, in this case, benefited this study because it increased the racial diversity among those who participated by including additional women who identify as part of a racial minority group, which would have been lacking otherwise.

When each interview officially began, the first set of questions I asked of participants were demographic and background questions pertaining to their self-described race, social class, age, education level, gender, occupation, relationship status, and the number of children they have. The demographics of the women in this study indicate a rather young population of females, with a higher-than-average level of educational attainment. The sample included in this study consisted of 15 women, who ranged from nineteen to twenty-nine years-of-age, with a mean age of 21.2. All women in this study have attended college, with some (n=3) having completed their Bachelor's degree. The median number of years of college completed was 3 years (n=4). Concerning social class make-up, this sample spanned a large range. Individual yearly income ranged from about $300 to $40,000. As most of the participants were also currently full-time college students, most (n=9) provided a sense of their resources by indicating their overall family income. The respondents' family income varied substantially, from approximately $20,000 at the lower end to $500,000 on the high end. About half (n=7) of respondents indicated they are in a relationship (but are not married) and none of the women had children. One woman in the sample self-identified as Hispanic, one as Black, eleven as White/Caucasian, and two people indicated they were biracial (one woman indicated she was Hispanic with indigenous roots and one woman did not specify any specific racial groups of which she was a part).

The final two questions included in the initial demographic and background questions concerned their level of contact with people with impairments both within their own families and in the workplace. When women in this sample were asked about whether they have any family members who have a disability, about half (n=7) mentioned that they have no family members with an impairment. Two women indicated they have distant, extended family who may have a disability, but they have little to no contact with these members of their family. About a third of participants (n=6) discussed at least one close family member (such as a parent, sibling, or cousin), that they interact with at least somewhat frequently, as having a disability. Impairments among the close family members included a wide array of conditions that encompassed both mental and physical health issues. The participants noted that their close family members had many types of impairments, including examples of mental illness (i.e. Schizophrenia, Depression, trouble with anger management), physical health conditions (i.e. amputations, unspecified work injuries, back pain/problems), and mental/learning impairments (i.e. Autism, Dyslexia, Down Syndrome, Attention Deficit Hyperactivity Disorder). Four of the six participants with family members who have a disability have multiple family members with impairments.

The last question I posed to participants related to their demographics or family background was whether they had ever worked at a job where they worked with people who have disabilities. A majority of respondents (n=11) mentioned that they had, indeed, worked for at least a short time with a fellow employee who had an impairment or worked at a job where the participant was in a care-giving occupation and took care of adults or children who had a disability. Some participants, for example, relayed that they worked in a kitchen area for a past job where there was another employee who had a speech impediment and a physical impairment that caused him to limp somewhat when he walked. Another participant worked as a camp counselor in a specific role where her main job task was to provide daily-life assistance to campers with impairments. All women who indicated they had worked around or specifically assisted people with impairments in a work environment discussed at least some direct interaction on a consistent basis with disabled people.

Data coding and analysis

This research was focused on gaining insight about the ways in which language was used to frame the discussion of potentially having a child with an impairment. Thus, interview respondents were asked to read through passages of text from some of the pregnancy guides selected for inclusion in the content analysis phase of this dissertation study. I asked participants to read two different passages and to discuss their perceptions of the overall tone they identified to best describe the passage.

Additionally, they were asked to delineate what specific language, terms, and phrases that led them to make that conclusion about the overall tone of the reading. These supplemental questions were asked as a check on the validity of the respondent's answer to the first question about the tone they perceived to be associated with each passage. The follow-up questions provided the participant the opportunity to reflect deeper on the passage and what they felt, specifically, made the passage seem more positive, neutral, or negative. In a sense, the women had to "justify" their initial categorization of the passage and its tone.

Analysis of data began during the data collection process. During the interviews, themselves, as I recorded the answers women provided to the interview questions, I began noting patterns of the participants' responses. The initial, manifest meaning conveyed by women in the study was apparent in most of the responses provided. The initial construction of categories of data began with the data collection process, as the data was initially encountered during the interviews. In the assessment of the manifest content of the data, I identified and noted patterns in the overall responses the participants gave about the tone of each passage. The first question asked appeared to provide a clear, simple answer indicating the respondent's feelings about whether the passage they read was more so positive, neutral, or negative. However, I then asked two follow-up questions that probed further into what, specifically, gave the participants their perception of the tone of the text they had read. Specifically, I asked participants to identify specific language/terms used in the passage to describe disability and the meaning they felt was associated with the language used in the passage. When I asked these follow-up questions, the answers provided by the women in the study typically matched their initial responses well. For example, some women indicated they felt the first passage was more so negative and they indicated that terms like “chromosomal problems,” “abnormal,” and “chromosomal defect” led them to the generalization that the information had a negative feel. This connection between a negative tone and terms that, by definition, indicate something is a “problem” or “abnormal” was more so straightforward. However, there were other times where a participant noted that the tone of a passage was “positive” or “neutral,” but then indicated that terms like “abnormal” and “defect” that were used in the reading displayed a more negative feel. This indicated a discrepancy between the overall tone that the woman felt was portrayed and the language they perceived to convey meaning about a disabled child. Further reading and rereading of the transcribed interviews allowed for an analysis of the latent content of the participant’s ideas.

In the later stages of coding, I reread the transcribed data multiple times (on different occasions) and notes were recorded about the deeper meaning and context of each respondent’s answers. This continued analysis of the transcriptions allowed me to identify a deeper understanding of the reflections provided by respondents (Berg 2004). Additionally, field notes recorded during the interviews, along with additional comments and information provided at various points during the interviews, helped give extra context for the perceptions of the passages noted by the participants.

CHAPTER V

CONTENT ANALYSIS FINDINGS

Introduction

This study was concerned with studying the ways in which information about having a potentially impaired child was constructed and perceived through discourse in pregnancy guidebooks. In the first form of analysis for this study, pregnancy advice books were examined as a means of gaining insight into the socially constructed context of information provided to parents-to-be about an unborn child's potential "health" or possibility of impairment. In this chapter, I highlighted an extensive set of examples that conveyed the clear patterns of discussion and themes presented within the discourse about potentially having an impaired child. I took the stance that it was imperative to examine the perspective of those in positions of power, who have been given the authority to help shape the context of information about the health status of an unborn child. Specifically, their assertions disseminated in popular pregnancy guidebooks was of focus for this dissertation research. Further, gaining the perspective of those who may be a potential future audience for these guidebooks, who may read the text and form meanings about the language used by the authors, was significant to analyze and will be outlined in Chapter VII. The potential audience's perceptions added complexity to the understanding of the meanings associated with the discourse in the pregnancy guides. Their perceptions also facilitated a check on the validity of the patterns and themes determined by myself to be present in the pregnancy guides, which are outlined in this chapter.

Information about impairment and disability in the pregnancy guides in this study was markedly framed in specific ways. The specific themes I identified as present in these texts included discussions of an unborn child having a potential impairment as: 1) something women and partners fear and worry about, 2) problematic and abnormal, 3) related specifically to the topic of “health”, and 4) something that is related to the field of medicine and something that should be handled by medical professionals. These themes were established after reviewing all of the initial themes and identifying the meaning-laden contexts of each piece of data. The themes I outline in this chapter were apparent throughout the texts and information was categorized in a straight-forward manner in order to highlight patterns in which the information was presented. I provide excerpts in this section to illustrate the ways in which information was presented in the pregnancy guides included in my sample. The discussion section in Chapter VIII outlines some of the consequences of the ways in which the information was presented.

Fear and Worry

A prominent thread woven throughout discussions of potentially having a child with a disability centered around being panicked and fearful of having such a child. The high frequency of terms and phrases such as “fear,” “cause for concern,” “worry,” “danger,” “threat,” “panic,” “freaked,” “risk,” and “dangerous” connected to having a child with an impairment indicated there was, perhaps, a great level of concern about such an occurrence. Another possibility is that the fear that was emphasized was not so much reflecting that parents-to-be *were,* in fact, concerned to some great extent, but that there was, at least, an emphasis given in the pregnancy guides that the authors felt that parents *should* be concerned about this "threat."

Generalized, consistent fears about pregnancy

Often, the content of terms and phrases about "risk" and "worry" were found in sections of the books specifically devoted to discussing feelings of fear about pregnancy, in general. A clear example of how this appeared in the pregnancy guides was found in *The Girlfriends' Guide to Pregnancy,* by Vicki Iovine (2007:60), when the author remarked,

> Fear is a common denominator among all pregnant women… Shortly after [the child is born], the fears become more specific. You don't just feel a huge, undifferentiated sense of worry, but you can list the individual things that terrify you from moment to moment.

Another example from the same book by Iovine (2007:63-64) came when the author was further discussing the extensive level of consistent worry for pregnant women and stated,

> Worry seems to be a necessary exercise for pregnant women, and for every bit of reassurance you get, you will substitute one more thing to worry about. Guilt provides all sorts of material for uncomfortable worrying in a pregnant woman. We become convinced that now is the time to pay the piper for all of the terrible things we did to ourselves in our carefree youth. If you, unlike most declared political candidates, actually inhaled when you smoked weed, you will feel faint at the prospect that your chromosomes are forever altered and your baby will have 12 toes. Imagine those of us who did worse things in the way of chemical experimentation! Unless we take the Girlfriends' advice, we have more than thirty-six weeks of worry ahead of us.

This context specifically appeared to relate worry about a physical issue arising in the unborn child as a result of retribution for past sins, as if a child with an impairment was a deserved punishment for poor personal decisions from a prior time in one's life.

Taking a less judgmental stance, but still associating worry and risk with personal behaviors women may have engaged in, Murkoff and Mazel (2008:71) mentioned in *What to Expect When You're Expecting* that, "The sooner a heavy drinker stops drinking during pregnancy, the less risk to her baby. The risks of continued drinking are definitely dose related: the more you drink, the more potential danger to your baby." Additionally, in the *Mayo Clinic Guide to a Healthy Pregnancy,* by Harms and Wick (2011:33), the topic of risk of having complications with pregnancy was discussed, this time connected with eating behaviors when the authors noted:

> Foods to avoid:… However, there are certain foods you should stay away from or limit because they could carry risk of unwanted side effects. The chance of a serious complication is small, but it's generally best to play it safe.

One further way in which these warnings of risk and potential harm to a pregnant woman and unborn fetus was found in the same text, *Mayo Clinic Guide to a Healthy Pregnancy,* when Harms and Wick (2011:51) noted:

> But don't be misled by the belief that just because herbal products are 'natural,' they must be safe… The fact is, herbal products need to be treated in the same manner as most medications- avoid them… Why? Because herbal products can be just as dangerous during pregnancy as traditional medications. They could even be more harmful because so little is known about many herbal supplements… Pregnancy is generally a time to play it safe.

Ensuring the safety of an unborn child (and specifically keeping it safe from the danger of impairment) was such a pronounced pattern in pregnancy advice books that authors Harms and Wick (2011:3) asserted in the Forward to their book *Mayo Clinic Guide to a Healthy Pregnancy* that, "This new person you're bringing into the world will become so important to you that you'll do anything to nurture and protect him or her." They immediately followed this statement with an emphasis on "ensuring a healthy pregnancy," which stressed the need to protect the fetus from poor health (i.e. having an impairment).

As all of these examples illustrated, there was a consistent reminder and belief shared with soon-to-be mothers that there is risk, worry, and danger associated with their actions that may lead to complications and altered states of "health" for their unborn children. Further, authors of pregnancy guides often dedicated a significant amount of space in their texts to associating worry, risk, and fear of problems with other types of behaviors in which parents engage, as well.

Dangers/fears revealed through prenatal testing

A common behavior among expecting women in the U.S. is to partake in prenatal testing. This event was connected strongly in the pregnancy guides with the topic of perceived or emphasized fear, worry, and distress among pregnant women. One illustration of this connection was outlined by Iovine (2007:89-90) in *The Girlfriends' Guide to Pregnancy* when the author discussed an alpha-fetal protein test and mentioned that,

> This test finds out if you have a higher than average risk of having a baby with certain birth defects such as Down syndrome or spina bifida. Don't freak… If this happens to you, DON'T PANIC. These results are usually considered *indicators* that there *might* be a problem- they are not usually the final word. We were all weak with fear and panic, but an amnio negated that result… Please keep this in mind, because all of us are prone to irrational fears about our babies, even before we meet them face-to-face… [Emphasis in original]

In the same section in this text, Iovine (2007:90) continued to discuss how "terrified" she felt expectant mothers would be when engaging in having these tests completed when she asserted:

> The reasons we are terrified of amnio's are threefold. First, with the long needle they use, we think it will hurt like a son-of-a-gun. Second, our genetics counselors or OBs have legally been obligated to tell us that there is a small chance of the test itself harming the fetus or causing [a] miscarriage... And third, the most agonizing of all, if the amnio tells us, God forbid, that her baby is genetically abnormal, we would have to decide whether to terminate the pregnancy. This is one of the most horrific decisions a couple will ever have to make, and the prospect of facing it is brain-twisting. After all, if you are absolutely against abortion, why get an amnio in the first place, unless you feel forewarned is forearmed?

In the above illustration, not only was the test, itself, worrisome, but the potential outcome, and socially imposed idea that expectant parents may need to make “horrific decisions” if less-than-desirable risks are identified, was also just as distressing.

Along with Iovine (2007), Murkoff and Mazel (2008) also mentioned worry and anxiety a great deal throughout their book *What to Expect When You’re Expecting* in conjunction with testing that is performed. An example of this pattern from Murkoff and Mazel (2008:65) came from a section on amniocentesis when the authors informed readers:

> You undergo screening tests for the reassurance you hope they’ll provide, but unfortunately, what happens so often instead... is a false positive. There goes the reassurance you were hoping to find—and here comes the needless anxiety and worry you were so hoping to avoid... What you’ll hear instead is this reassuring news…

While much stress was placed upon the risks, fear, and dangers imposed during pregnancy due to past or current individual behaviors or because of prenatal testing performed, there was also an emphasis given to a related issue: reassurance.

Safely navigating dangers

In pregnancy guidebooks, pregnancy was certainly connected to the stresses of potential dangers lurking at every turn, but the authors also noted many points that are aimed to provide assurance that some things are *not* risky or will *not* pose the threat of harm to a pregnant woman and her unborn child. Thus, these texts still addressed the broader topic of there being fear of dangers and risks being associated with their unborn child, but in a different light that affirmed certain behaviors as lacking danger or an eminent threat to the mother and child, therefore arguing that certain acts were "safe."

The Girlfriends' Guide to Pregnancy provided an example of this pattern in a section that discussed women who had more tests performed in addition to the initial prenatal tests when Iovine (2007:84) stated, "Having more or fewer than these [initial] tests is not in itself a cause for worry." Other pregnancy guides offered examples of the same kinds of reassurance related to prenatal tests. An example that conveyed the safety of having a specific test completed during pregnancy was relayed in *What to Expect When You're Expecting,* by Murkoff and Mazel (2008:65), when they answered a frequently asked question about amniocentesis by confirming, "How safe is it? Amniocentesis is extremely safe; the risk that the procedure will result in a miscarriage is believed to be as low as one in 1,600." An additional example of how Murkoff and Mazel (2008:59) included information about the reasons testing should not be feared was seen in a section on genetic counseling when the authors relayed:

> The best reason for prenatal diagnosis is the reassurance it almost always brings. The vast majority of babies whose possibly-at-risk moms undergo such testing will receive a perfect bill of health—which means that mom and dad can quit worrying...

Authors of these pregnancy guides clearly placed an emphasis on the reassurance testing may provide, rather than solely emphasizing the fear of danger parents can, or should, have about testing related to their pregnancy and unborn child.

The offer of reassurance was not confined to helping expectant mothers feel more comfortable with forms of prenatal testing, but extended to other realms of pregnancy, as well. An example of a way in which an author of the pregnancy guidebooks asserted a sense of safety for expecting parents was when Harms and Wick (2011:59), in *Mayo Clinic Guide to a Healthy Pregnancy,* indicated that, "The flu shot is made from an inactivated virus, so it's safe for both mother and baby during any stage of pregnancy." Further, Murkoff and Mazel (2008:125) delineated the safety of, and need for, good dental hygiene if a woman is pregnant when they stated, "Pay a visit to your dentist for a cleaning and a checkup; most dental work, particularly the preventive kind, can be done safely during pregnancy and may actually prevent pregnancy complications."

Whether the discussion surrounding fear, worry, and threats involved constructing the notion of dangers being present or offered reassurance in the face of a perceived threat, a significant point was that these discussions all centered around the assumption that fear of danger and risk was present (or should be present) for expecting parents. All of the above examples, among numerous others, denoted much trepidation about what pregnancy may entail or about, specifically, having prenatal tests performed. The definitive cause of fear, and the reason authors perceived that expectant mothers needed reassurance, was often directly related to what the results of risks, harms, or the prenatal tests may lead to: a child with a possible impairment or health "problem." When authors of these pregnancy guides discussed topics related to prenatal screening and having a "healthy" child in these ways, it has the potential impact of asserting a sense that either expecting parents *are* anxious or worried about what the tests would reveal or that they *ought to be* fearful of some "abnormality" in the pregnancy and/or the unborn child.

Impairment as Problematic and Abnormal

The pregnancy guides in my sample were full of terms and phrases related to disability that signified impairment as inherently "abnormal" and as a "problem." Using language that specified impairment as a problem and abnormal was seen in these texts when authors stated terms and phrases such as: "chromosomal problem," "fetal abnormality," "complications," "low IQ problems," "poor quality life," "defect," and "not normal." Additionally, any part of the text that identified specific names of impairments, such as "Down Syndrome" or "Tay-Sachs" were included in this category. The justification for this was that these conditions were frequently paired with other terms listed above, such as "chromosomal defect" or "fetal abnormality." Discussions using the above-mentioned terms and phrases permeated the pregnancy guides in my sample and provided a clear connection between those who are impaired and a sense that impairments are always abnormal and impaired people are thought to be defective or abnormal. Additionally, authors connected the idea of potentially having a child with an impairment as a "complication" of pregnancy, again pairing terms with a negative connotation to having a child with a possible disability.

Impairments included as complications

There are many things that can occur before, during, or after pregnancy that could either lead to complications or be considered a complication, itself. When authors discussed the topic of what may have occurred in a woman's previous pregnancies, authors Harms and Wick (2011:20), in *Mayo Clinic Guide to a Healthy Pregnancy,* advised pregnant women to, "Be sure to mention any complications you may have had, such as high blood pressure, gestational diabetes, preterm labor or birth defects," which equated birth defects with a complication. In the same pregnancy guide, authors Harms and Wick (2011:4) provided an overview of the different sections of their book, relaying that Section 6 of the book was concerned with complications of pregnancy and childbirth, stating that, "Most pregnancies proceed smoothly, but sometimes problems can develop in mother or baby. The most common complications, and how they're treated, are discussed here." Authors Harms and Wick (2011:109), in *Mayo Clinic Guide to a Healthy Pregnancy*, also discussed "possible complications" associated with multiple births when they stated that one potential issue related to preterm labor and, "New babies that arrive early have a greater chance of being low birth weight (less than 5.5 pounds) and having other health complications." On this same subject, in a later section of the same book, Harms and Wick (2011:164) discussed babies that may come too early, noting that, "…it's comforting to know that almost all babies born at this age will survive without life-threatening complications." Implicit in all of these examples was the connection made between potential impairments or health issues in the unborn fetus and the notion that it conferred a “complication” exists in the unborn child.

The discussions relating potential impairment in an unborn fetus to a complication were also found in another pregnancy advice book, *What to Expect When You’re Expecting* (Murkoff and Mazel 2008). Murkoff and Mazel (2008:72) covered ways in which smoking could cause issues to arise during pregnancy when they noted that:

> The results can be devastating. Smoking can increase the risk of a wide variety of pregnancy complications, including among the more serious of these ectopic pregnancy, abnormal placental implantation, premature placental detachment, premature rupture of the membranes, and possibly early delivery.

In a discussion about low birth weight in new infants in *What to Expect When You’re Expecting,* Murkoff and Mazel (2008:412) mentioned that, “…babies born weighing less than 3 pounds are at increased risk for health complications as newborns, as well as for long-term disabilities.” In a later section of the same book, Murkoff and Mazel (2008:536) discussed numerous other proclaimed “complications” of pregnancy when they stated in the beginning of a chapter titled “Managing a Complicated Pregnancy:”

> Pregnancy complications: The following complications, though more common than some pregnancy complications, are still unlikely to be experienced by the average pregnant woman. So read this section only if you’ve been diagnosed with a complication or you’re experiencing symptoms that might indicate a complication.

Although this generalized statement appeared to lack a direct connection between a woman experiencing a complication and a child potentially having an impairment, the vast majority of the complications listed in this chapter involved health issues that pose a higher “risk” for miscarriage or a health issue for the unborn child, such as birth defects. As I outlined in the next section, having a child with a disability was heavily associated with not just “complications,” but as connected to other negative terminology, such as “abnormality” and “defect.”

The “problem” with impairments

Although there are many examples in the texts in my sample that illustrated the ways in which impairment was discussed as a “complication,” I restricted myself here to examples that illustrated the most common types of statements about the “problems” with impairment. In a discussion of why different types of prenatal tests are important, Murkoff and Mazel (2008:60) stated in *What to Expect When You’re Expecting* that, “Increased fluid *may* indicate an increased risk of chromosomal abnormalities such as Down syndrome, congenital heart defects, and other genetic disorders.” [Emphasis in original] As illustrated by this example, multiple terms indicating the problematic issues associated with impairment (i.e. “abnormalities”, “defects”, “disorders”) were used together, which may have served to reinforce the extent of abnormality that is associated with having an impairment. In another section of this same book, Murkoff and Mazel (2008:73) discussed issues related to smoking during pregnancy and reminded mothers:

> Consider, too, that some of the deficits- physical and intellectual- linked to maternal smoking and drinking don't always show up at birth but often years later (a seemingly healthy infant can grow into a child who is often sick, who is hyperactive, or who has trouble learning).

Here, the author paired "deficits" and "trouble" with her unborn fetus potentially having a disability in later life. An example found a bit further into *What to Expect When You're Expecting* relayed a deeper connection to a more extensive list of terms with negative meanings when the authors, Murkoff and Mazel (2008:77), conferred information about the potential impact of cocaine use during pregnancy, stating:

> It is also believed to lead to birth defects, miscarriage, premature labor, low birth weight; jitteriness and withdrawal-like crying in the newborn- as well as numerous long-term problems for a child, including neurological and behavioral problems (such as difficulty with impulse control, with paying attention, and with responding to others), motor development deficits, and possibly lower IQ scores later on in childhood.

In this example, the authors connect the possibility of having a child with a disability to terms like "defects," "problems," "difficulty," and "deficits." One final illustration of this trend from the same book by Murkoff and Mazel (2008:555) indicated similar kinds of connections between having an impaired child and this indicating something negative (like "problem" and "defect") when they stated, "…when fluid accumulation is severe (which is rare), it may signal a problem with the baby, such as a central nervous system or gastrointestinal defect, or an inability to swallow (babies typically swallow amniotic fluid)."

An additional example of this pattern of using multiple terms with negative meanings assigned to having a child with an impairment was seen in *Mayo Clinic Guide* *to a Healthy Pregnancy* when Harms and Wick (2011:19) noted that, “Folic acid helps prevent neural tube defects. These defects are serious abnormalities of the brain and spinal cord.” This statement was then followed by a similar message by Harms and Wick (2011:20), “Taking prenatal vitamins before conception is the best way to help prevent neural tube defects, which can result in spina bifida and other spinal or brain disorders,” which provides heavy emphasis equating an impairment with “defective,” “abnormal,” and as a “disorder.” In a later section of the same book, when authors Harms and Wick (2011:97) provided information about the potential impact of stress on pregnancy, they noted that, “Typically, early miscarriage is caused by a fetal chromosomal abnormality or another problem in the development of the embryo… Other causes of repeated early miscarriage may include: Chromosomal abnormalities in either parent.” The term “abnormality” was used in a way that connects having a chromosomal of developmental condition with lacking normalcy. A final example from *Mayo Clinic Guide to a Healthy Pregnancy* that showed this emphasis on unborn children having “abnormal” traits was seen when Harms and Wick (2011:315) discussed amniocentesis and stated that:

> Although amniocentesis is accurate in identifying certain genetic disorders, it can’t identify all birth defects. For example, it can’t detect a heart defect, autism, or cleft lip and palate. A normal result from an amniocentesis may provide reassurance regarding certain congenital problems, and it doesn’t guarantee that your baby is free of all defects.

In this example, the authors connected negative terms like “disorders,” “problems,” and numerous instances of “defects” with a child that may have an impairment. Additionally, the authors noted that the amniocentesis test may allow parents to feel "reassurance" that there isn't something wrong with their unborn child, such as it having a disability.

In *What to Expect When You're Expecting,* Murkoff and Mazel (2008:71) also discussed the topic of potential impairment in the unborn child with several terms that have negative connotations when they asserted:

> Heavier drinking… throughout pregnancy can result not only in many serious obstetrical complications but also in fetal alcohol syndrome (FAS). …This condition produces infants who are born undersized, usually mentally deficient, with multiple deformities (particularly of the head and face, limbs, heart, and central nervous system) and a high mortality rate. Later, those who survive display vision, learning, behavioral, and social problems, and they generally lack the ability to make sound judgments.

Another example of how authors presented information about how impairments were the cause of a miscarriage that has occurred, indicating the extent to which impairments are problematic. This can be viewed in a section on complications during pregnancy when Murkoff and Mazel (2008:539) stated, "Most often, miscarriage is simply a random one-time occurrence caused by chromosomal abnormality, infection, chemical or other teratogenic (birth defect-causing) exposure..." On a similar note, the author of *The Girlfriends' Guide to Pregnancy,* Iovine (2007:60), indicated that, "The vast majority of miscarriages that occur in the first trimester are the result of a genetic malformation of the embryo…"

These statements, while perhaps based on real patterns (that a condition or impairment is so problematic that it often makes a fetus incompatible with life), may have also emphasized other socially imposed notions, namely that those with impairments are “not normal” or are “imperfect.”

Judgmental statements about “abnormal” fetuses

There were many places in the pregnancy guides analyzed where the authors included value judgments about the “normality” (or lack of normality) associated with an unborn child that may have a disability. What was clear from these examples was that having a child with an impairment is often thought to indicate an inherently problematic state that is seen as less than desirable. Iovine (2007:105) relayed information about abnormal fetuses leading to miscarriage when a fetus is not “normal” in *The Girlfriends’ Guide to Pregnancy* when she mentioned:

> It is widely believed that about half of all miscarriages occur because the fetus was not normal. Thus comes the most common, and least comforting, comment that woman who has just miscarried will receive: ‘Don’t worry, dear. This is just nature’s way of weeding out the imperfect ones.’

The same author, Iovine (2007:106), noted a similar judgment about the notion that distress would be inherently connected with potentially having an impaired child when she noted, “Even if you don’t endanger the pregnancy, if something (God forbid) goes wrong, you will forever wonder if your exercising caused it.” In another statement in the same pregnancy advice book, Iovine (2007:61) described the fear that she perceived parents must have about an unborn child that may have an impairment when she asserted:

> Your sometimes uncontrollable fear that your child may be born less-than-perfect is your first inkling of how vulnerable you will be regarding the well-being of your baby… It is impossible to stop rerunning the brain tape that plays out what you will do if something is less-than-perfect with your baby. This is because you are certain that if something happens to your child, you will have no other option but to die yourself.

Whether the author's declaration, here, reflects parents' perceptions or were more so an assertion she felt parents have/should feel was not known. However, it was clear that she was making an assertion that was based on a judgment about the perceived normalcy or "less-than-perfect" state of a child if it had "something wrong with it," such as an impairment. The points here indicated that parents would rather die than experience such a reality.

Authors of the other pregnancy guides in my sample included similar discussions. Some authors used terms indicating they were making a judgment about what is "normal," though did not include as much negative context in their discussion as was discussed above. In *What to Expect When You're Expecting,* Murkoff and Mazel (2008:515) stated that if an expectant mother was seeking out the right kind of medical care, "…your chances of having a normal pregnancy [are good]." In a later section of the same book, Murkoff and Mazel (2008:527) also noted, "There's good news for both you and your baby. Women with MS [Multiple Sclerosis] can definitely have normal pregnancies…" When discussing the topic of complicated pregnancies, Murkoff and Mazel (2008:533), again, commented on normalcy during pregnancy when they mentioned, "Our friends and relatives may lend a sympathetic ear when you need one, too, even if their own pregnancies were more ‘normal’ and they can’t always relate.” A final example of a discussion in *What to Expect When You’re Expecting* that centered around what is “normal” was conveyed when Murkoff and Mazel (2008:539) outlined information about miscarriage, stating: “Happily, the chances are excellent the next time around you’ll have a normal pregnancy and a healthy baby.” What was conferred in this statement was that what is “normal” is to have a baby that is fully healthy which, in a later section of this analysis, clearly means that it is free of impairments. This offered a judgment about what was seen as a “happy” outcome versus “other” outcomes, which implied that an “unhealthy” child was seen as an inherently negative and unwelcome reality.

The *Mayo Clinic Guide to a Healthy Pregnancy,* by Harms and Wick (2011:241), also emphasized that it was undesirable, or not “normal,” to have a child with a disability when the authors noted information about congenital hypothyroidism, when they stated that, “About one in 3,000 babies have a thyroid hormone deficiency that slows growth and brain development. Left untreated, it can result in mental retardation and stunted growth. With early detection and treatment, normal development is possible.” In another section of the same book, Harms and Wick (2011:247) included subjective reflections about the lack of desirability of an unborn child having an impairment when they presented information about premature newborns, stating:

> Every parent dreams of having a healthy, full-term baby. Unfortunately, that dream isn't always the reality. Although most infants are born full-term and free of medical problems, some are born too early. Prematurity- defined as being born before 37 weeks gestation- is often, though not always, accompanied by medical complications.

When discussing prenatal screening and the likelihood of complications in pregnancy in *Mayo Clinic Guide to a Healthy Pregnancy,* a similar emphasis on an unborn child potentially having an impairment was emphasized by Harms and Wick (2011:307) when they pointed out that, "Most results from prenatal testing come back normal, which can help ease any anxiety you may be feeling [about potentially receiving abnormal results, indicating a child may have a risk of impairment]." In a later section on pregnancy loss and miscarriage, authors Harms and Wick (2011:471) again conveyed perceptions about the lack of normalcy in impaired fetuses when they noted:

> Most miscarriages occur because the fetus isn't developing normally… Problems with the baby's genes or chromosomes typically result from errors that occur by chance as the embryo divides and grows… Some examples of abnormalities include… Intrauterine fetal demise: This situation may also be due to genetic abnormalities within the embryo.

In an additional section of the *Mayo Clinic Guide to a Healthy Pregnancy,* Harms and Wick (2011:481) relayed information about the problem of molar pregnancies and indicated that if a woman has experienced one with a previous pregnancy, she can have a test performed with the current pregnancy in order "…to make sure that the pregnancy is normal." Further, discussions about potentially having a child that has "abnormal" qualities in these pregnancy guide books often times included an emphasis on expectant parents needing to decide whether to keep the unborn child or abort it due to its “deviant” health status.

Needing to decide whether to terminate an “abnormal” fetus

There were a multitude of passages that conveyed an emphasis on a connection being present between a test result indicating a possible abnormality and an inherent need for parents to have to make a decision about whether to continue on with, or terminate, the pregnancy. One clear illustration of this pattern was found in *Girlfriends Guide to Pregnancy* when the author, Iovine (2007:91), pointed out three key reasons as to why expectant mothers are afraid of amniocentesis testing when she mentioned:

> And third, the most agonizing of all, if the amnio tells us, God forbid, that her baby is genetically abnormal, we would have to decide whether to terminate the pregnancy. This is one of the most horrific decisions a couple will ever have to make, and the prospect of facing it is brain-twisting… if, like most of us, you are unsure where you stand on terminating pregnancy, hearing that your fetus is not viable will quickly force you to decide.

In this example, the author conveyed the perception that, “God forbid,” a fetus has a potential impairment (or “abnormality”) because this would “force” parents to make a life or death decision about whether to continue on with or “terminate” an unborn child’s life. In the same text, Iovine (2007:170) made a similar statement later in the book, again related to amniocentesis testing, when she stated:

> The secrets that no one will tell: Some “miscarriages” are not spontaneous abortions, as the medical books call them, but rather are the result of searingly painful decisions that the parents must make- usually in such shame or fear of being judged harshly that they carry the burden silently… The first type occurs when amniocentesis or CVS… indicates that the unborn child is genetically defective. The second type occurs more and more with the frequency of multiple embryos and is called selective termination.

As is the case with the first example from Iovine (2007:170), this second illustration used terms that indicated parents are “forced” into making decisions about whether to terminate a pregnancy or that they “must” make these “painful” decisions. This type of language used asserted that having to make such a decision is inherently present when testing is performed and there is a chance that the fetus may have some sort of condition or impairment.

The other pregnancy guidebooks included in this analysis also offered similar examples of the emphasis on parents needing to consider the termination of their unborn child if it is impaired. In *What to Expect When You’re Expecting,* Murkoff and Mazel (2008:67) mentioned this issue of parents needing to know about things that are potentially “wrong” with their child, and options they have, when they noted that:

> In the vast majority of cases, prenatal diagnosis yields the results that parents hope for- that all is well with their baby-to-be. But when the news isn’t good- when something does turn out to be wrong with their baby- the information provided by such a heart-breaking diagnosis can still be valuable to parents. Teamed with expert genetic counseling, it can be used to make vital decisions about this and future pregnancies.

Harms and Wick (2011:297), in *Mayo Clinic Guide to a Healthy Pregnancy,* proposed the idea that parents need to “make decisions” if their fetus is suspected to be at risk of an impairment when they stated,

> Prospective parents who are worried about possible genetic disorders and their children can undergo genetic screening before or shortly after the baby is conceived. With this information, potential parents can consider what the risk is of having a child with a genetic disease and make decisions accordingly.

As a follow-up to the information noted above, Harms and Wick (2011:297) suggested parents consider a series of questions about prenatal tests in order to make the best decision about whether to proceed with further testing, including: “Will the time it takes to complete the test give you adequate time to make decisions regarding beginning or continuing a pregnancy?” When this information was framed in this way throughout pregnancy advice books, it seemingly argued that having to make a decision about terminating a “less-than-normal” fetus is a reality that needs to be realized by expecting parents. As indicated in the above illustrations, other options were often not discussed in these pregnancy guides. There are, however, a couple of notable exceptions to the rule in *What to Expect When You’re Expecting* (Murkoff and Mazel, 2008) and *Mayo Clinic Guide to a Healthy Pregnancy* (Harms and Wick, 2011).

One illustration of a case where one of the pregnancy guides offered a more complete picture of some of the options that parents have after having prenatal tests performed was when Harms and Wick (2011:306) stated that:

> You may be faced with decisions you never expected to have to make, such as whether to continue the pregnancy. On the other hand, knowing about a problem ahead of time may give you the option of planning for your baby's care in advance.

This was one of few places where authors of these texts indicated that an additional possible option after prenatal testing that indicates an "abnormal result" is to continue with the pregnancy and use the advanced "warning" as a way to prepare for the care of such a child. This type of emphasis had a slightly different context, allowing expectant parents to conceive of keeping the child and having time to explore resources and other help in taking care of a potentially disabled child.

Another illustration of this theme was seen in *What to Expect When You're Expecting*, where Murkoff and Mazel (2008:67) discussed a similar point in a special box titled "If a Problem is Found," when they mentioned:

> [Continuing the pregnancy is an option] often chosen when the defect uncovered is one the couple feels that both they and the baby their expecting can live with, or when the parents are opposed to abortion under any circumstance. Having some idea of what is to come allows parents to make preparations both emotional and practical for receiving a child with special needs into the family, or for coping with the inevitable loss of a child. Parents can also begin working through the reactions (denial, resentment, guilt) that can come with discovering their baby has a problem, rather than waiting until after delivery. They can learn about the particular problem in advance and prepare to ensure the best possible life for their child. Joining a support group- even one online- can help make coping somewhat easier.

These two illustrations from two of the pregnancy guides indicated a clear break from the previously noted pattern of an emphasis on terminating the pregnancy of a potentially impaired child. Here, the authors noted a different reality that parents may face- that they could consider continuing on with their pregnancy and use the time they have to explore information, resources, and/or support in keeping and caring for their unborn child that may have a disability. This context seemingly highlighted a more complex set of options for expectant parents, rather than the more one-sided option of terminating the pregnancy of a “risky” fetus.

Lack of Impairment Equated with Health

It was common for authors of the pregnancy guides in my sample to use terms related to health synonymously with terms related to not having an impairment. For example, authors frequently stated that a fetus was “healthy,” when in fact they were referring to the fetus’s lack of birth defect or impairment within the context of the information they discussed. Terms and phrases used in these circumstances included examples such as: “baby was born healthy,” “genetic health,” “healthy baby,” “growing up healthy,” “lack of health complications,” and “health of your baby.” Connecting understandings of health with lack of impairment was seen in numerous discussions throughout the pregnancy guides included in my sample. First, I outline ways in which the pregnancy advice books emphasized either the realistic focus of parents or the authors’ own perception that parents should be worried about the health of their baby, above all else. Next, I highlight the ways in which authors of these texts stress the role of prenatal testing as a way to reveal the state of an unborn child’s “health” to its expectant parents.

A primary focus on having a "healthy" baby

Throughout all of the pregnancy advice texts in this analysis, authors highlighted the notion that the most important goal of pregnancy was to have a "healthy" (i.e. non-impaired) child. Indeed, the *Mayo Clinic Guide to a Healthy Pregnancy* included this emphasis on a "healthy pregnancy" right in the title of their book! This emphasis was followed up a few pages into their book in the forward when the Harms and Wick (2011:3) stated that, "You want to do all you can to help ensure a healthy pregnancy and a wonderful beginning to your child's life." In *What to Expect When You're Expecting*, Murkoff and Mazel (2008) relayed information about this topic using health-related terms, but indicated the need to consider the "health" of a future child even before a couple conceives. The "health" of a potential future child is so significant, that a woman needs to work ceaselessly to provide a possible child a healthy "vessel" (i.e. the woman's body) during the woman's child-bearing years, in case they become pregnant. In the first pages of Murkoff and Mazel's (2008:2) book, in fact, a discussion of the importance of preconception care arose and the authors asserted that, "...before sperm meets egg to create the baby of your dreams, take this preconception opportunity to prepare for the healthiest pregnancy—and baby –possible." Right from the beginning of these pregnancy books, expecting parents were introduced to the vast wealth of information that would follow about how to have a "healthy" baby.

In another section of *What to Expect When You're Expecting*, amid the considerable amount of discussion of the health of a fetus, Murkoff and Mazel (2008:58) asserted that, "...the one question that expectant parents wonder about the most is also the one they're most hesitant to speculate on or even talk about: 'Will my baby be healthy?'" In *The Girlfriends' Guide to Pregnancy,* Iovine (2007:60) made a similar statement about the emphasis on the health of an infant being the ultimate goal of pregnancy when she stated, "The most important rule of pregnancy is THIS IS NOT A CONTEST! YOU JUST DO WHAT YOU CAN TO SURVIVE THE NINE (TEN) MONTHS AND HAVE A HEALTHY BABY" [Emphasis in original]. As with my earlier question in the first portion of this findings section concerning the fear and anxiety parents are purported to have about their unborn child, it was relevant to ponder if parents do really wonder so much about their unborn child's "health" or if medical professionals and other experts who wrote these pregnancy guides manufactured this "wonder" and anxiety.

In *What to Expect When You're Expecting* (Murkoff and Mazel 2008)*,* the authors also contextualized a "healthy" baby as one without impairments when they discussed potential conditions in infants related to whether a pregnant mother consumes dangerous substances, such as alcohol. An illustration of where the authors included this assertion was seen when Murkoff and Mazel (2008:70) outlined the dangers unborn children are exposed to, such as Fetal Alcohol Syndrome (FAS), mental deficits, and physical deformities when a mother drinks during pregnancy. Murkoff and Mazel (2008:70) mentioned, though, that for some women, a minimal amount of drinking during pregnancy could also lead to women who "…delivered perfectly healthy babies." In a proceeding section about the potential dangers of cigarette smoke on fetuses, Murkhoff (2008:72) again pointed out that affected infants are more likely to be at risk for conditions like Sudden Infant Death Syndrome (SIDS) and apnea, and reported that "…they aren't as healthy at birth as babies of non-smokers." On the next page of the same pregnancy guidebook, the authors relayed that although some children may be more likely to come early, and babies that arrive early may pose extra concern, parents can work to improve their chances of having "…a perfectly health, full-term bundle of joy" that is free of "complications" (Murkoff and Mazel 2008:73). In the same special box in which these authors discussed the topic of "complications" that may arise with a baby that arrives early, Murkoff and Mazel (2008:73) indicated some of the possible complications as including "deficits- physical and mental," which includes being "sick" more often and a child that has "trouble learning," which suggests developmental delays. In a final example from *What to Expect When You're Expecting,* Murkoff and Mazel (2008:578) clearly connected the notion of a "healthy" baby with having a child that is free of impairments when they mentioned that even though a woman may have experienced a miscarriage due to complications, they stated, "Try to remind yourself that you can- and most likely will- become pregnant again and give birth to a healthy baby."

The Girlfriends' Guide to Pregnancy also included points that conveyed a similar emphasis on a "healthy" child not having an impairment when Iovine (2007:105) proclaimed that, “Tragically, not all pregnancies result in the delivery of a healthy baby…” amid discussion of miscarriages being likely among fetuses that are “not normal.” Thus, it was argued that if a child didn’t make it, it was likely because the fetus had something “wrong” with it; thus, ill health was equated with incompatibility of life. Additionally, this same author drew a connection between a child being unhealthy and parents looking negatively upon this outcome for the child. When Iovine (2007:61) discussed fears parents would have that their child may be born “less-than-perfect” (such as born without the proper number of fingers, toes, etc.) in *The Girlfriends’ Guide to Pregnancy,* she stated that, “If your baby is not happy and well, neither are you.” Here, the author indicated in the context of the discussion that a child born without being in the perfect physical state would be unhealthy and unhappy. She also suggested to parents that they would be dissatisfied with their child if it was born with a health issue of some kind. As noted in previous sections, it is unknown whether parents inherently feel this way or not, but it is clear that unhappiness was presumed to be felt by parents considering the context of this assertion by Iovine (2007).

Equating health with being free of an impairment was also emphasized in the *Mayo Clinic Guide to a Healthy Pregnancy* (Harms and Wick 2011). Toward the beginning of the pregnancy guide book, Harms and Wick (2011:20) indicated that doctors will help expectant women “…boost [their] chances of a healthy pregnancy.” In the same section, the authors noted that, “Good nutrition and exercise create the ideal environment for creating a healthy baby” (Harms and Wick, 2011:20). These initial points stressed that there was an emphasis in pregnancy on creating a healthy "environment" for the fetus so that it could be free of impairments when born. However, the authors' dialogue lacked a transparent mention of wanting to create the healthy body to develop within *as a means to avoid impairment*; instead, the authors used the term "healthy" to denote a child free of impairment.

In a later section when the authors outlined (mostly negative) consequences of a woman having a child in later life, they consistently mentioned an increased risk of "complications" (i.e. impairments) and, in the midst of the same discussion, also underscored the perception that an unhealthy child and an impaired child were the same thing. This was seen when Harms and Wick (2011:30-32) asserted that:

> If you're in your 30s or even 40s, you can still have a healthy pregnancy and a healthy child… Risk of chromosomal abnormalities is increased: Babies born to older mothers have a higher risk of certain chromosome conditions, such as Down syndrome… Miscarriage risk increases as you get older, perhaps due to the higher likelihood of chromosomal abnormalities… Steps toward a healthy pregnancy are the same for women age 35 and older as for younger women. To reduce your risk of complications and help ensure a healthy pregnancy at an older age…

In this illustration, the authors highlight the idea that chromosome conditions and abnormalities are more likely in later life, which poses an increased risk of complications in regard to health.

When discussing potential issues that may arise due to a woman taking birth control at the time that she conceives a child in a later section of *Mayo Clinic Guide to a Healthy Pregnancy*, Harms and Wick (2011) again contextualized "health" and impairment as inherently contradictory terms. In a special box that addressed this topic of potential risks associated with taking birth control, Harms and Wick (2011:51) mentioned that, "According to the American Congress of obstetricians and gynecologists, taking birth control pills during pregnancy doesn't increase the risk of birth defects… Keep in mind that most babies are born healthy with no problems." In this example, the authors drew a clear distinction between a child that has a risk of birth defects and those born healthy. In an additional example within the same pregnancy advice book, Harms and Wick (2011:224) again indicated the difference between having a "healthy" child and one that was impaired when they began a section titled "Baby has a health problem" and noted that: "If your baby has been diagnosed in the womb with a health condition, such as spina bifida…" a C-section may become likely. Another illustration of this type of discussion was found in the *Mayo Clinic Guide to a Healthy Pregnancy* when Harms and Wick (2011:305) conferred information about reasons parents often give as to why they do or do not want to partake in prenatal screenings, stating:

> Still, in some instances you may wish to know specific information about your baby's health before his or her birth. Perhaps because of your age or family history you may be at increased risk of carrying a baby with a chromosomal problem or some other genetic disorder.

In this example, the authors indicated parents may want to have screenings completed because they felt they needed to know about the "baby's health" due to potential "chromosomal problems" or a "genetic disorder." Similar to previous illustrations discussed, the authors paired the idea of *health* with *chromosomal or genetic conditions*, which posited the assumption that to have an impairment leads to ill health. Discussing information in this way may help to establish the notion for expecting parents who read these pregnancy guidebooks that an impaired child is intrinsically unhealthy. This type of emphasis by established authorities (i.e. the authors of pregnancy advice books) can influence decisions these parents make about their unborn children, who they perceive as either “healthy” or not, in part based on discussions like these in pregnancy guides. Often, when authors made such statements that equated “health” with a child free of impairments, they also asserted this connection as related to something that is revealed through images from prenatal testing.

Health status of the fetus conveyed by prenatal testing

Authors of the books in this sample used health terms in place of clarifying that they were discussing impairment all throughout the pregnancy guides, especially in sections where the authors mentioned information about prenatal testing. The authors often highlighted the significant role the tests played in revealing “health” information (i.e. the presence, or lack of presence, of an impairment) for the unborn child). The conversations about screenings typically revolved around their ability to “reveal” potential outcomes to medical professionals and parents. Although, there is also some discussion of problems with the ability of the screenings to accurately convey an unborn child’s actual health status.

One clear example of the pregnancy guides in this sample having conveyed the relationship between prenatal tests and assessing fetal health was found in the *Mayo Clinic Guide to a Healthy Pregnancy*. Authors Harms and Wick (2011:305) conveyed that, "Whatever the reason [you are offered prenatal screening], certain tests can help determine the health of your baby while he or she is still in your womb. These are called prenatal tests." In another section of the same pregnancy guide, Harms and Wick (2011:115) mentioned that, "…your care provider may talk with you about prenatal testing for fetal abnormalities. Prenatal tests are performed to assess the health of your baby, generally by way of a blood test or ultrasound exam." Harms and Wick (2011:67) provided advice to partners of women who are pregnant, encouraging them to be present for prenatal visits, stating, "An ultrasound gives you a glimpse of the baby in utero and helps to confirm the baby's healthy…" On a similar note, the author of *The Girlfriends' Guide to Pregnancy* clarified that, "Amnios, as we vets refer to them, test the genetic health of your unborn baby..." (Iovine, 2007:90). An additional example of this pattern, where authors connected testing with revealing the "health" of an unborn child, was seen when Murkoff and Mazel (2008:584) discussed realities of "pregnancy reduction," noted that:

> Sometimes an ultrasound reveals that one (or more) of the fetuses in a multiple pregnancy can't survive or is so severely malformed the chances of survival outside the womb are minimal- and worse yet, that the ailing fetus may be endangering your other healthy one(s).

In this type of case, where one or more of the children in utero may have "poor health" and may be a threat to "healthy" children, doctors discussed the option of pregnancy reduction, or the termination of "unhealthy" fetuses, with the expecting parent(s). This exemplified a case where prenatal screening was indicated as the means to assess unhealthy versus healthy children, and the tests were also used to help doctors and parents make life or death decisions about which fetuses are desirable.

The pregnancy texts in this sample also made mention of the fact that the prenatal tests, although providing useful information about a fetus's health, also failed to provide wholly accurate information at times. In *The Girlfriends' Guide to Pregnancy,* when Iovine (2007:95) provided information about specific types of prenatal screening, she stated that, "All in all, 95 percent of all women having amnio or CVS will go on to have a healthy baby..." Here, the author indicated that the tests, themselves, were unlikely to cause or increase the risk of impairment in an unborn fetus. However, instead of using straight-forward phrasing, such as lack of "impairment" resulting from having the tests completed, the author emphasized that parents went on to have a "healthy baby." Additionally, the author brought attention to the fact that some tests may reveal a potential risk or health condition in the fetus, but others contradict the initial results/tests and offer different insights. In *The Girlfriends' Guide to Pregnancy,* within a discussion about Iovine's friend who had an initial prenatal test that revealed that her baby may have had an increased risk of Down Syndrome, Iovine (2007:90) stated "…but an amnio negated that result, and her baby girl was born healthy and at her due date." A final illustration from *The Girlfriends' Guide to Pregnancy* that demonstrated this emphasis on screenings used a means to convey a fetus's health when Iovine (2007:66) wrote:

> Though 'soft markers' on an ultrasound (detected during 5 to 10% of second-trimester ultrasounds, depending on the marker) are subtle characteristics that may indicate an increased risk of a chromosomal problem (most often Down syndrome or trisomy 18), these characteristics are also found in plenty of babies who are perfectly healthy.

While this example illustrated the clear distinction between those infants that were "healthy" (or lacking an impairment) and those that were "unhealthy" (or had increased risk of a chromosomal problem), it also conveyed the lack of accuracy of tests. Harms and Wick (2011:306), in *Mayo Clinic Guide to a Healthy Pregnancy,* also highlighted the lack of validity in prenatal tests when they asserted that: "Even if a test indicates a risk, the majority of women will have a healthy baby. Thus, a screening test may cause unnecessary anxiety." The authors provided the perception that the "risk" of an unhealthy (i.e. impaired) child may cause "anxiety" among expectant parents due to the lack of accuracy of a test.

What to Expect When You're Expecting (Murkoff and Mazel 2008) followed a similar pattern as the other pregnancy guides when it discussed the use of screenings to assess an unborn child's health being potentially misleading. One illustration of this conversation as it was presented in this guidebook was when Murkoff and Mazel (2008:65) mentioned that even negative results on a prenatal screening could be deceiving because the vast majority of mothers given the indication that there is a potential risk of their infant having an impairment would have "…normal and healthy babies." Thus, even though screenings could help provide insight into a child's health, the tests are, also, not always accurate. In an additional example by Murkoff and Mazel (2008:297), they outlined dozens of impairments that could be screened for with prenatal tests and noted that these tests reveal that, "Most babies are born healthy and stay that way. But [a reality is that] a very small percentage of infants are born apparently healthy and then suddenly sicken." The authors drew a direct connection between infants being healthy and then becoming "sick" with a condition that caused an impairment, indicating there is a difference between being "healthy" and having an impairment (i.e. a sickness). Additionally, this example highlighted, again, that screenings are not always reliable in conveying a child's overall current health or future health outcomes.

Impairment as Related to, and Handled by, Medical Professionals

A final pattern I identified as a common theme concerning ways in which authors discussed disability in pregnancy guides concerned their assertions that medical professionals are involved with identifying and addressing needs related to an impaired fetus. As the previous theme emphasized, having an impairment was often equated with being "unhealthy" and, as was stressed with this next theme, health matters require medical knowledge and assistance.

One prominent way in which this theme was incorporated in the pregnancy guides was when authors posited, through use of language and the context of their dialogue, that pregnant women (and their unborn fetuses) need experts in order to interpret information and to make decisions regarding the “health” of the child. In this same regard, the authors frequently used official titles that conferred authority to the professional (such as “expert” or “specialist”) or used the official title of the source of information (such as by using the title of a government or research entity that provides the data they discussed). The second means by which the authors of these pregnancy texts asserted a connection between the health of the fetus and the need for medical professionals was when they emphasized consultation, advice, and treatment by trained professionals. A key argument posited by the authors was that this involvement by professionals leads to “healthier” outcomes for the fetus through a more extensive level of monitoring and observation by medical personnel. This subtheme was the most consistently displayed throughout the pregnancy advice books. A final, notable way in which the authors of these books integrated this theme into the conversation was when they conferred the increased capabilities of tests and medical staff to provide an extra layer of insight about health to the expecting mother, along with the increased benefits of this information and the ready availability of these tests and information.

Experts needed to treat issues with impairment in the fetus

Throughout the pregnancy advice books in my sample, the writing in the books conveyed that those with authority (i.e. medical experts) are essential resources for expecting parents when they have questions about the health (or health needs) of an unborn child. When conversing in the pregnancy guides about the many potential "health" risks in fetuses, authors often used the phrase "ask your practitioner" or "ask your genetic counselor," and posed the question "what can you and your practitioner do?" (Iovine, 2007:90; Murkoff and Mazel, 2008:64; Harms and Wick, 2011:32). When authors used this particular kind of phrasing, along with the broader context in which these statements resided, the authors reminded the reader that she needs to refer to a medical professional for help with matters related to her child's "health." Additionally, the authors made it appear natural and a given in the question posed above that it is not just a parent that interprets and makes a decision about what is best for a child's health, but that there is no question that the practitioner is an integral part of the decision-making process.

This same point was reiterated in similar ways in other places throughout the pregnancy guides in different contexts. Even before a woman conceives a child, it was argued that she should trust medical professionals to assist her in preparing her body for pregnancy and in working to identify/prevent poor "health" outcomes in the future, potential child she conceives. In *Mayo Clinic Guide to a Healthy Pregnancy*, Harms and Wick (2011:18-20) argued the need for women to take part in preconception visits (i.e. a medical/genetic check-up before she conceives a child) with a professional, when they stated:

> A preconception visit gives you and your care provider a chance to identify any potential risks to your pregnancy and establish ways to minimize those risks… If you or your partner has a family history of a genetic disorder or may be at risk, your care provider may refer you to a medical geneticist or a genetic counselor for a preconception assessment.

In Chapter 1 of *What to Expect When You're Expecting* (Murkoff and Mazel 2011), titled "Before You Conceive," the authors outlined a number of precautionary steps a woman should take part in so she can try to ensure a low risk of health issues in her potential future child. Murkoff and Mazel (2008:2-3) asserted that, before conceiving, a woman should:

> Get a preconception checkup… it would be a good idea to see your regular gynecologist or internist for a thorough physical… your doctor will be able to steer you away from medications that are pregnancy (or preconception) no-nos… [And] Start looking for a prenatal practitioner.

In these examples, the authors stressed the importance of getting practitioners involved in the process of pregnancy, even before the pregnancy is a reality. This illustrated the extent of reliance the authors perceived that women should have on medical professionals in the quest to have a child free of "health" complications.

The need for having professionals attending to health concerns in the unborn child, in general, was indicated in *What to Expect When You're Expecting* when Murkoff and Mazel (2008:64) mentioned that after prenatal screening has been performed, parents should "…be sure an experienced physician or genetic counselor has evaluated the results" before the parents have made any decisions on their own. In a later section of the same text when outlining information about testing that has indicated increased risk of chromosomal problems in a fetus, Murkoff and Mazel (2008:578) argued that, "Your practitioner may suggest some more tests (like an amnio) to find out for sure… [Though] most experts advise that ultrasound be used in pregnancy only when a valid indication exists [that one is needed]" because the initial testing procedures used are not always accurate.

In the *Mayo Clinic Guide to a Healthy Pregnancy,* Harms and Wick (2011:32) included a similar dictate, as well, when they noted that expecting mothers should, "Ask [their] care provider's advice about the benefits and risks of each [type of prenatal] test." In another section of the *Mayo Clinic Guide to a Healthy Pregnancy,* Harms and Wick (2011:221-224) also pointed out the need for medical professionals to be involved in pregnancy and health matters in the unborn child when they discussed C-sections, stating:

> Sometimes, abnormal fetal heart rate patterns occur without indication of any real risk to your baby. At other times, the findings can indicate a serious problem. One of the most difficult decisions in obstetrics is determining when the risk is genuine… If your baby has been diagnosed in the womb with a health condition, such as spina bifida, your care provider may recommend a C-section.

A final illustration of this theme was found in the same text in a later section when Harms and Wick (2011:247) discussed children that are born prematurely that may be experiencing medical/health problems, making note of the scariness of the setting, remarking that, “This equipment may be overwhelming and intimidating. It’s important to remember that it helps keep your baby healthy and the medical staff informed about your baby’s condition.” These kinds of statements by Harms and Wick (2011) and Murkoff and Mazel (2008) are integrated into the texts in such a way that made it seem natural to take the advice of medical experts because the use of technology, testing, procedures, and medications is assumed to be intimidating/too complex for expecting parents to understand on their own. Additionally, as noted with the discussion of the first theme identified in this chapter, pregnancy can be fraught with safety concerns and fear, so medical professionals with expertise in pregnancy need to be involved.

A similar dictate was offered amidst information about pregnant women potentially experiencing issues with their sugar levels (such as hypoglycemia or diabetes) in *The Girlfriends’ Guide to Pregnancy* when Iovine (2007:88) argued that expectant mothers would need to “…watch [their] diet and strictly follow [their] OBs directions…” Another illustration of an author of one of the pregnancy guide books positing that expectant mothers are expected to need, and follow, expert advice about the health of their unborn child was seen in *Mayo Clinic Guide to a Healthy Pregnancy* (Harms and Wick 2011). Authors Harms and Wick (2011:58-65) offered answers to a common question asked by readers concerning what to do if an expectant mother fell during pregnancy when they noted:

> After approximately 24 seeks, a direct blow to the abdomen can cause complications and must be evaluated… If you're worried about the welfare of your baby after a fall, see your healthcare provider for reassurance… Your care provider may want to run some tests to make sure everything is OK.

In *The Girlfriends' Guide to Pregnancy*, Iovine (2007:90) also pointed out that if an expecting mother had an initial test completed that indicated an increased risk for birth defects, like Down syndrome, "… [she] may get a call from the doc to go back in for another test." These statements indicated a directive being given by a doctor when there was a question or concern about the unborn child's "health" and an expectation on the part of the doctor that the mother will comply with the summons. The order has been given by a doctor, the expert about these kinds of issues, so it is assumed that it is normal to comply, and is expected, of the pregnant woman.

The *Mayo Clinic Guide to a Healthy Pregnancy* (Harms and Wick 2011) contained the most extensive and consistent emphasis on the need for involvement by experts in order to make decisions about testing for "health" problems in unborn children and in the process of making decisions about the fetus. In the Forward to the book, in fact, Harms and Wick (2011:3) began their book with a statement confirming their expertise and level of authority about all things related to pregnancy and health when they stated: "*Mayo Clinic Guide to a Healthy Pregnancy* is an authoritative reference manual that you can trust." Stressing the importance of the authors' authoritative assistance offered in the pregnancy guidebook was also posited by Harms and Wick (2011:4) when they mentioned that, "During pregnancy, you may be confronted with a number of decisions, big and small. Part four [of this book] is designed to help you determine the best option for you in your particular situation." From the beginning of the book, the authors conveyed the need for this guide and the authoritative knowledge that the authors can provide in times of need, such as when there is a "health" risk to the fetus. Additionally, the authors of the pregnancy guides sometimes used official titles of medical organizations and government agencies when discussing prenatal screening and the need to look for "health" issues in unborn children. This emphasis conveyed an additional sense of authority to the medical profession. An illustration of this pattern was seen in the *Mayo Clinic Guide to a Healthy Pregnancy* when Harms and Wick (2011:240) discussed prenatal screening tests, noting that, "The American College of medical genetics recommends a panel of tests to check for 29 targeted diseases. Some states perform tests to check for additional diseases."

Harms and Wick (2011:26) continued the emphasis on the need for involvement of medical professionals in a similar vein by including a lengthy discussion toward the beginning of their book concerning the process of "choosing a care provider," which argued that,

> Once you've made the decision, you'll know that you chose your care provider for a reason. Trust his or her abilities to safely guide you and your baby through the birthing process, and allow your provider to give you the best possible care.

This statement directly connected the safety and well-being of the unborn child with a skilled professional that should be trusted. Taken together, all of these statements normalized the presence of the authoritative experts in the pregnancy experience and encouraged expectant mothers to trust in the information and advice the professionals provide about health matters. Further, these professionals were displayed as being equipped with the ability to “handle” situations that arise with pregnancy, such as “ill health” in an unborn child. These professionals were portrayed as a given, or necessity, in circumstances where there was a potential risk that the fetus may have, or develop, an impairment.

Often, the authors of the pregnancy guides in this sample extended the dialogue about needing skilled professionals involved in pregnancy to include those who have special expertise in the field, namely those who are *specialists*. Harms and Wick (2011:28), in *Mayo Clinic Guide to a Healthy Pregnancy,* stated that although a family physician may be used to handle most pregnancy care, “…if [an expecting mother] had problems with pregnancy before, [her] family physician may refer [her] to a specialist in obstetrics or use a specialist as a backup provider.” Additionally, they extended this conversation about specialists to include information about more severe circumstances where “complications” in a fetus’s health are more likely when Harms and Wick (2011:28) mentioned that:

> Maternal-fetal medicine specialists are trained in the care of very high-risk pregnancies. They concentrate exclusively on pregnancy and the unborn child, dealing with the most severe complications… This highly specialized doctor is familiar with the complications of pregnancy and adept at recognizing problems. When women with major medical concerns become pregnant, their physicians often consult with maternal-fetal medicine specialist to optimize care for both the mother and her baby.

In the same text, in a section outlining numerous details about prenatal screening, Harms and Wick (2011:306) posed issues for the audience to ponder when considering whether they decide to go through with different forms of testing, which include:

> At times, prenatal testing can provide information that affects your care. Testing may uncover a problem with your baby the doctors can treat while you're pregnant. It may alert your care provider to a problem that requires a specialist to treat your baby right after he or she is born.

Although most discussion of the topic of needing a specialist to attend to health related issues concerning the child were about in-utero problems, authors also included dialogue about the need for medical expertise after a child is born. For example, in a section titled "Thinking Ahead: Finding a Care Provider for Your Baby" in the *Mayo Clinic Guide to a Healthy Pregnancy,* Harms and Wick (2011:150) mentioned that, "A pediatrician can be particularly helpful if your child has a health condition or needs special medical attention." In a later section of the *Mayo Clinic Guide to a Healthy Pregnancy,* Harms and Wick (2011:247) included an outline of medical specialists who may attend to a newborn that has intensive care needs after birth, noting: "The team attending to your baby may include: Neonatal nurses- registered nurses with special training in caring for premature and high-risk newborns… [and] Neonatologistspediatricians who specialize in the diagnosis and treatment of problems of the newborn."

It is clear from all of the examples included in this section that there was a heavy emphasis throughout the pregnancy guides that women, and their unborn children, need the assistance of expert medical professionals. Much discourse interspersed in the pregnancy guides steered expecting parents toward those officials that can provide much needed advice on health matters of a child before, during, and after pregnancy.

Professionals providing consulting and reassurance about a child's health

The pregnancy advice books in this sample included extensive information relaying the important role of medical professionals, consultations, and testing during a woman's pregnancy. There was a specific emphasis in these books on the need for medical professionals to "monitor," "consult," and "treat" (or provide treatment for) an unborn child. This need was expressed in the context of professionals being essential in order to watch over, and work to prevent or "fix," health issues that arise in unborn children. In regard to where information about this topic was located, it was interspersed throughout the texts. The information about the central role of medical professionals was found in many different sections because the guide books were often set up in a way that took the reader from the initial stages of pregnancy to the end, with discussion of medical issues that may arise at different times during pregnancy throughout the book. As pregnant women tend to have different needs at different stages of their pregnancy, the role of medical professionals was discussed throughout the entire book as the different stages of pregnancy were covered.

One way the authors of the pregnancy guides in this sample highlighted the importance of having medical professionals involved in pregnancy in order to watch over an unborn child was when they stressed the need for doctors to evaluate, monitor, and provide directives about treatments for expecting mothers. A clear illustration of this pattern was seen in *the Mayo Clinic Guide to a Healthy Pregnancy* when Harms and Wick (20011:105) discussed the need for prenatal checkups, stating: “If you have a chronic health problem, such as diabetes or high blood pressure, you may need more frequent visits to monitor your health and your baby’s health.” In the same text by Harms and Wick (2011:49-51), when they outlined the need for expecting mothers to tell their doctors about the medications they take, they noted that,

> [Your care provider] can help you evaluate what’s safe to take before, during and after pregnancy… Your care provider will advise you on the best way to stop taking a medication [that may be dangerous] and how long you may need to wait before it is safe to conceive.

When discussing specific health problems that may develop during pregnancy, Harms and Wick (2011:441) made a similar point when they mentioned that, “Careful monitoring and early intervention often can lessen the dangers faced by growth-restricted babies.” Additionally, in the *Mayo Clinic Guide to Pregnancy,* authors Harms and Wick (2011:216) argued that, even after a child has been born, medical professionals are needed as consultants in order to provide guidance in case there are health issues when they noted: "…if your baby shows any signs that help is needed, such as trouble breathing, he or she may need to be evaluated more thoroughly in the nursery." These illustrations demonstrated the emphasis placed on the significance of having health professionals involved in evaluating an unborn child's health and in providing treatment if there is a risk identified.

Another example of ways in which the authors stressed the need for professionals to be involved in evaluating fetuses appeared in *What to Expect When You're Expecting* related to how parents can best "manage a complicated pregnancy" when Murkoff and Mazel (2008:560) noted that, "If you've been found to have a two-vessel cord, your pregnancy will be monitored more closely, since the condition comes with a small increased risk of poor fetal growth." Here, the authors stressed that if there is a chance for a health complication in the fetus, medical professionals are needed to monitor the situation so that issues can be identified. Additionally, when discussing prenatal tests and the potential "problems" that might be detected through the testing in *The Girlfriends' Guide to Pregnancy,* Iovine (2007:85) noted that, "Remember, all of these things, if detected, can be dealt with safely; you may just need to work more closely with your doctor to take care of yourself and your precious little baby." A similar assertion was made in the *Mayo Clinic Guide to a Healthy* Pregnancy by Harms and Wick (2011:303) when they conversed about genetic screening results and stated that, "If an increased risk is indicated [in the genetic screening], your care provider, a geneticist or a genetic counselor can help you understand the implications of the disease and assess your options." Not only did Iovine (2007) and Harms and Wick (2011) indicate that a doctor needs to be consulted for evaluation of an unborn child, but that they will "deal" with problems if they arise by providing treatment.

All of the above illustrations helped to indicate a pattern of discussion presented in the pregnancy guides, where the authors posited that pregnancies and, specifically, unborn children need to be evaluated by professionals through evaluation and monitoring. This may give the audience of these guide books the impression that it is necessary to have surveillance performed on their unborn child in an attempt to identify and "fix" problems in the fetus. These "problems" are health conditions that indicate an impairment is present and are seen as worth the effort to consult with professionals and attempt to prevent or treat them.

An additional way in which the authors of the pregnancy advice books analyzed in this study highlighted the necessity of having medical professionals consult with women during pregnancy was illustrated when they stressed the feeling of reassurance women can gain from the involvement of doctors. Not only should women consult with health professionals, but these doctors can provide a sense of comfort that everything (including fear of "problems" in the infant) can be detected and corrected. Further, professionals were noted as being able to provide a healthier outcome for the pregnancy and the infant. For example, Harms and Wick (2011:65), in the *Mayo Clinic Guide to a Healthy Pregnancy,* argued that, "If you're worried about the welfare of your baby after a fall, see your healthcare provider for reassurance." In a later section of the same text, Harms and Wick (2011:443) discussed problems of labor and childbirth, noting that:

> Even if you're doing everything right as you go through labor and child birth, complications can occur. If something does go wrong, trust that your care provider in your healthcare team will do the best for both you and your baby.

With the type of message conveyed in these examples, the audience receives the advice to not only trust medical professionals, but to find faith/hope in what medical professionals can offer in regard to monitoring a child's health and in providing treatment.

In *What to Expect When You're Expecting,* Murkoff and Mazel (2008:514-515) made a similar assertion when discussing women who have specific health conditions, asserting that:

> While it's true that a severe asthmatic condition does put a pregnancy at somewhat higher risk, fortunately, this risk can be almost completely eliminated. In fact, if you're under close, expert medical supervision- by a team that includes your obstetrician, your internist, and or your asthma doctor- your chances of having a normal pregnancy and a healthy baby are about as good as a non-asthmatic's (which means you can breathe a little easier now).

Additionally, Murkoff and Mazel (2008:125) provided a related message when they noted, "Women who see a practitioner regularly during pregnancy have healthier babies, and they are less likely to deliver prematurely and to have other serious pregnancy-related problems." A final example from Murkoff and Mazel (2008:300) that provided an illustration of the significance of medical professionals being involved in order to provide hope for better health in the fetus is found when they discussed premature babies, mentioning that, "And when a baby does turn out to be small, the top-notch medical care currently available gives even the very smallest an increasingly good chance of surviving and growing up healthy." With these kinds of statements, the authors assured readers that medical professionals are able to ensure a healthy outcome in an infant and can provide reassurance to expecting mothers.

Another way in which the advice books stressed the need for medical professionals to, specifically, monitor a fetus and provide reassurance and better health for the child was seen in places where the authors outlined the need for technology as a means to surveille the unborn child. An illustration of this was seen in *What to Expect When You're Expecting* when Murkoff and Mazel (2008:79) pointed out that if parents are concerned about potential harm that may have been caused by the pregnant mother spending time in a hot tub while pregnant, they can "…speak to [their] practitioner about the possibility of having an ultrasound exam or other prenatal test to help put your mind at east." It was noted by the author that parents' concern can be assuaged by medical professionals through the use of technology and parents should be consulting with professionals in order to have the testing performed. Later in the same text when Murkoff and Mazel (2008:413) conversed about placental problems/ complications that may occur when a mother has a multiple birth (such as twins, triplets, etc.), the authors pointed out that:

> Fortunately, careful monitoring (which you'll be getting) can detect previa long before it poses any significant risk. Abruption can't be detected before it happens, but because your pregnancy is being carefully watched, steps can be taken to avoid further complications should an abruption occur.

In *The Girlfriends' Guide to Pregnancy*, Iovine (2007:225) included an emphasis on the need for technology (used by professionals) once the parents are checked into the hospital when labor begins in order to help parents understand whether their child is doing alright or not, when she mentioned, "Please be warned that changing positions, either yours or the baby's, can interfere with the monitor's ability to detect the heartbeat. *This does not mean that anything is wrong with the baby"* [Emphasis in original]. While discussing prenatal tests that can be performed during pregnancy in the *Mayo Clinic Guide to a Healthy Pregnancy*, Harms and Wick (2011:310) made a related point when they noted, "In some situations, such as a high-risk pregnancy, ultrasounds may be repeated throughout the pregnancy. They can be used to monitor the health of both the mother and the baby and to track the baby's growth."

Harms and Wick (2011:319) provided additional, similar illustrations of the ability of technological testing to help professionals monitor the health of a fetus when they stated, "Biophysical profile testing helps you and your care provider keep track of your baby's health before delivery, particularly if you have a high-risk pregnancy." A further example of this pattern was seen when Harms and Wick (2011:203) outlined information about fetal monitoring during labor when they noted that, "Specific patterns [on the monitor] suggest that labor may be negatively affecting your baby and intervention may be needed." In a final example from Harms and Wick (2011:427), they provided an additional illustration of an emphasis on technology allowing doctors to provide reassurance for parents when the authors mentioned that:

> Further testing may be recommended to monitor the health of the fetus. If the level of antibodies becomes too high, steps can be taken to prevent harm to the baby. They may include blood transfusions to the fetus while still in the uterus or, in some cases, early delivery.

In all of the examples included above, the authors indicated that monitoring the fetus was necessary in order to prevent health issues in the child and that if professionals are integrated into the careful screening of an unborn child, parents can be reassured that other complications can be avoided. Without their presence, parents may end up having a child with "complications" in regard to the fetus's "health," exemplifying why professionals are so necessary.

CHAPTER VI

INTERVIEW FINDINGS

Introduction

This study is focused on gaining insight into ways in which the topic of potentially having a child with an impairment was presented in pregnancy guides. Beyond gaining insight about the discourse offered by authors in the pregnancy advice books about this topic, this research also aimed to gain insight into the perception a potential audience may have of this discourse. The perception women of child-bearing age have of the information presented in these guides was important to investigate because it offered an additional lens with which to understand the discourse presented by authors in the pregnancy guides, as well as to understand whether the interpretation of the message varied from the intentions of the writers. A potential audience offered an interpretive evaluation, beyond my own analysis, of the conversation authors of pregnancy guides presented on the topic of possibly having a disabled child.

In this chapter, I present patterns of responses from participants in the interviews for this study and I offer examples of interpretations the participants had of the discourse in the pregnancy guides included in this research. The examples I include are used as a means to highlight the ways in which a potential audience of these books might perceive the messages conveyed by authors in the pregnancy guides. It is significant to make note of the understandings a potential audience had of this discourse, and the meanings they associated with the language used by the authors of the guidebooks, because it gives light to varying ways in which information can be interpreted by those who encounter it. The examples I outline in this chapter indicate clear patterns of perception the participants have of the passages they read and themes concerning how they feel about the use of language used by the authors to contextualize the possibility of having a child with an impairment.

Initial Assessment: Meaning of Having a "Healthy" vs. an "Unhealthy" Child

As part of the interview phase of this research, before participants read through passages selected from the pregnancy guidebooks, participants first answered questions that mostly centered on hypothetical scenarios concerning the health of an unborn child. The first initial assessment questions I asked were: "If you were pregnant (or your partner was pregnant) and the doctor told you that tests have come back indicating you are having a healthy child, how would you react to that?" and "What meaning would you associate with them saying you are having a 'healthy child?'" These initial questions were followed by questions presenting a different scenario: "What would you think if the test results had, instead, indicated there is a chance, or risk, of having a child with a disability, such as Down Syndrome?" The last set of assessment questions concerned whether the participant had ever read any part of a pregnancy guidebook before and, if she had, she was asked: "How do you feel that this information helped shape how you feel about having a 'healthy' versus an 'unhealthy' child?"

This phase of the interview was completed immediately following the questions that gathered demographic information. The reasons these initial assessment questions were important was two-fold. First, beyond outright asking participants before the interviews began if they were comfortable discussing the topic of this research, I wanted to further ensure that they did not display signs of distress about the topic by asking about hypothetical situations concerning the potential of having a child with an impairment. At the initial assessment stage, if any participants indicated they were uncomfortable with the topic at hand or showed visible signs of being upset by the questions, we could stop the interview. An additional reason for including the initial assessment questions was to provide a base understanding of how the participants felt about the possibility of having a "healthy" versus an "unhealthy" child.

During the initial assessment questions, none of the 15 respondents indicated that they were bothered or anxious about the topics discussed. Other than two women indicating they would be unhappy to find out they were pregnant because they don't want to have children, regardless of its health, no participants were concerned with the overall topic of conversing about having a "healthy" or "unhealthy" child.

Perceptions of having a hypothetical "healthy" child

Women's reflections about how they would feel to be told they were having a "healthy" child were centered on two clear themes that emerged through the language they used to describe their reactions. One pattern that became apparent was an emphasis on feeling positive emotions. Specifically, women interviewed in this study proclaimed they would be “excited,” “happy,” “relieved,” “grateful,” and “glad.” In addition to using language that conveys happy, or positive, sentiments about the possibility of having a healthy child, several women displayed a keen awareness throughout the interview of the social desirability of having a healthy child. These women conveyed that they understood that our society places an emphasis on the idea that women should expect and want to have a healthy child and that this is what is “normal” for expecting parents to hope for. This was a notable pattern that emerged in statements from the participants in this study. At this stage of questions in the initial assessment, one participant, for example, stated that, “I think having a healthy child is [hoped for] as the norm… there is also a stigma with… disability.” This pattern became even more apparent when participants were asked to discuss the meaning they associated with being told they were having a healthy child.

When articulating the meanings they associated with having a “healthy” child, specifically, the responses of the participants in this study followed two distinctive patterns in their responses. One theme of the meanings they assigned to the idea of a “healthy” child centered on the child embodying physical health. For example, one specific example of statements incorporated by a respondent emphasized this pattern clearly when she stated, “I would think of physical health… At that state of the game, I would primarily think… the predictable appendages are present. Very base physical.” In a similar vein, another woman relayed that she would think the child was “…fully formed, like forming, functioning correctly, like system's intact." Yet another participant used similar language, with an emphasis on "normal" when she stated "My child would [have] normal functioning… that pretty much sums it up: normal." Another woman in the study focused more specifically on health in conjunction to heart issues, when she relayed that a "healthy" child has "…no complications. Health, when I say 'healthy' [I mean] heart disorder… heart defects and stuff like that. It means you can take them home pretty much right away." Conveying a broad, general outlook on what it means for a child to be "healthy," another woman stated that the child "meets all the… criteria, so like: healthy weight, breathing, [and] all that." Although the women in this study followed a clear pattern by indicating they felt health revolves around a child's physical realities, this was not the only factor that indicated health.

Many participants also framed the meaning of a "healthy" child as a child who is free of a disability or impairment. Indeed, a majority of respondents (n=9) included mention of a child who has no impairment as a child who is in good health. In this theme, participants identify what it means to be "healthy" by indicating what it is not; a "healthy" child is one that lacks a "health" problem, such as an impairment. One clear illustration of this theme comes from a woman who stated, "I would assume that… they don't have a disability at all." This point was also conveyed by a participant that articulated that a healthy child is one where, "The child doesn't have any noticeable physical, extraordinary physical disabilities or known genetic diseases." One participant connected a lack of physical health conditions in a child along with the child being free from impairments when she noted that a healthy child, “meets all the whatever, criteria, so like: healthy weight, breathing, [and] all that… And they don’t have any impairments, like any physical or mental.” Another woman argued that a healthy child “…[doesn’t] have any severe genetic disabilities or that they’re not more prone to getting sick.” On a similar note, another woman argued that:

> …if they’re ‘normal,’ I guess, and healthy then they’re not going to be facing any health issues, as well as like social issues, where they’re going to have problems, either physically or mentally. [They are] free of any health issues… like they don’t have any genetic things that are going to make them… not able to perform daily functions and things like that.

One participant expressed that she perceived a “healthy” child to not have any impairments, but articulated that it is difficult to know the range of conditions that doctors could identify at an early stage in a fetus’s development when she noted:

> I’m not exactly sure what they can tell at that point, I know they can tell if they have Down Syndrome or something but obviously not that [the child] is not having any physical problems, like… deformities. I know there’s some things you can’t tell from [early tests], like some… mental things that aren’t in place during birth. But from what [medical professionals] can tell, [a child] without any things that may negatively… or make their life more challenging [would be ‘healthy’].

Another participant noted that determining a child’s health was a complex issue, noting that a “healthy” child is one where:

> Just nothing too serious is going on, I guess… I could understand if it was something small… obviously there’s some things you can’t diagnose in the womb… So, I guess just nothing being seriously wrong that they can detect right now, like if they had, I don’t know, some type of physical issue like a cleft [palate] or something or other… But, I wouldn’t consider that ‘unhealthy’ if they’re okay, if they can still breathe and everything… Except a physical deformity.

The final illustration that exemplified this theme also highlighted a running theme throughout the interviews conducted, namely that some participants indicated an understanding of socially imposed expectations about the desirability of having a healthy child. One woman illustrated these points when she noted that a healthy child "…wouldn't need some sort of accommodation, that [is] what society has seen as kind of a burden, so I think that [would be] relieving."

Perceptions of having a hypothetical child with a risk of impairment

When conversing about the perceptions participants' have of being told they are hypothetically having a child with a risk of an impairment, like Down Syndrome, the women in this study conveyed a different theme in their responses to what they conveyed about potentially having a healthy child. Women indicated that potentially having an "unhealthy" child would invoke negative emotions. The most common initial reactions to the potential of a fetus having a disability was "worried," "afraid," "a little nervous," "very sad," and "it would be a downer at first." Beyond these initial reactions, however, the participants in this study elucidated what, precisely, would cause them to be upset and most women did not cite the health of the child. Instead, women tended to emphasize that negative reactions from others (in society) would be what would cause them distress. Additionally, some women conveyed they would be concerned about the extra work/resources (such as time and money) needed to help take care of a child with an impairment. Lastly, others emphasized that they would be worried because they didn't have enough information about specific impairments, resources for families with a disabled child, etc. The women that followed this last pattern suggested needing to conduct research in order to feel more comfortable with having a disabled child and as a means to provide them with adequate resources.

One illustration that clearly displayed the theme of being concerned about others' responses to their disabled child was expressed when a participant mentioned, "[I would be] concerned about my ability to meet their needs [and] how they would be treated in society." Another woman communicated a similar worry when she noted:

> I would be very sad [if my child had a risk of an impairment]… I'm an emotional person, just because it is my child and the possibility of [not being] normal, [not] being able to function and having to protect my child from people who don't understand disabilities would really scare me because kids are cruel and they do make fun of people who are not the same… Looking further down the line, I would just, really be sad cuz I would always have to protect my child from anyone hurting my child, just because they're different.

With a slightly different tone, another woman in my sample expressed her concern regarding how others treat those with disabilities in a negative way, but articulated a potential positive in the situation when she mentioned:

> I mean, I would kind of be surprised, I guess [to be told I was having a child with a risk of an impairment]… I think I would just look at it as, you know, this is what God wanted me to do and I'm going to do it. I would be terribly sad… I'm sure the first couple days [I would be in a] shock or whatever. Once [that] wore off, I think I would more embrace the opportunity. Cuz, ya know, there's children all over the world that are born [with] Down Syndrome and it's not good for them so I guess I'd be happy that it came to me.

Some participants went beyond discussing social stigmatization as a cause for concern and also mentioned the need for resources as something that worried them. One woman, for example, stated: “I would be a little nervous at… what I would do, maybe how I would pay for the child as it’s growing up.” One participant expressed a strong aversion to having children at all, mostly due to financial strain, so she indicated that if she was given the news that her unborn child was at risk of an impairment, she would consider an abortion. She specifically remarked:

> I know that, socially, the idea of having an abortion or something like that… is negative, but considering I don’t want children in the first place, having a child with something like Down Syndrome… would definitely sway me even more towards having an abortion… Cuz I just don’t, like especially being working class, I wouldn’t have the time or money to be able to take care of myself or the kid.

It is significant to note, here, that this participant had also indicated a negative emotional response to the first question in the initial assessment, concerning how she would feel if her hypothetical child was “healthy,” as well. Thus, the negative feelings associated with having an “unhealthy” child were not entirely due to its health state, as she articulated in the above statement, but because of her strong desire to not have any children.

Another pattern of response offered by women in this study included wanting to do research and working to “get ready” for having a child with special needs. One participant noted that she “…would probably start to have to prepare, like get books, knowledge, [and] research.” In a separate interview, a different woman relayed almost the exact same reflection when she mentioned, “I’d probably look into it more [and] do some research.” A third participant indicated a similar sentiment, though outlined more details about the preparation she would undertake, stating:

> I suppose that I’d probably be just as happy [as having a child deemed “healthy”], but I would definitely want to mentally prepare myself and make my environment at home more accessible for a person of the corresponding disability. Like, I don’t know, if they saw that [my child was] going to have some deformity of their legs, I’d make sure that my home was wheelchair accessible or maybe if they had a developmental disability, I’d make sure that the school district I was in had a good Special Ed. program.

When another woman discussed her feelings about being told she may be having a child with an impairment, she expressed more worry and concern that she wasn’t prepared, but also identified that the worry she felt was, in part, because of negative feelings others have about disabled people. She articulated:

> I would be very hypersensitive to [possibly having a child with an impairment]… because I’m unfamiliar, I wouldn’t say I’m an expert on any disability, I would be very afraid. I would probably do as much research, try to ask as many questions, as possible because it’s unfamiliar but there is also a stigma with disability…

Not only did she relay that she would feel the need to investigate more information available about having a disabled child, but also exhibited awareness of extra complications/stress associated with having a disabled child because disability is stigmatized.

Past encounters reading pregnancy guides

Because it could not be assumed that the women in this study had never read any part of a pregnancy guide before, the final part of the initial assessment in these interviews inquired into whether the participants had ever read pregnancy guides in the past. Of the 15 women in the study, 3 had encountered at least some small section of information from a pregnancy text at a previous time. Each person who had read part of one of these texts in the past had a different perception of the information presented that they read in the book. Additionally, each woman had varying outlooks on whether, and how much, it impacted their thoughts on having a healthy versus an unhealthy child.

The first woman who indicated she had read a few brief parts of a pregnancy guidebook previously mentioned that she felt "…the information they provided [was] all slanted towards having a healthy child and, so someone who isn't in that position will, might probably feel excluded or alone." In this reflection, the participant expressed negative sentiments toward the context of information presented by author(s) in the guidebook and had a preconceived notion that the book emphasized having a "healthy" child as normal/desirable too much.

The second participant who had encountered larger sections of at least one pregnancy guidebook in the past expressed that she really liked babies, so she had read parts of at least one book just for enjoyment. When discussing whether she felt the information in these books had shaped her feelings about having a healthy versus unhealthy child, she relayed: “I think more of life experiences are what would shape [my perceptions] more, just by working with kids that have special needs and working with kids that don’t have special needs [and] just comparing them. They seem equally difficult.” This perspective seemed significant in that it highlighted that perceptions about having a child, that does or does not have an impairment, is shaped by many factors, not just information with which we interact in texts. However, it is also important to consider that perhaps most people do not have the same kinds of opportunities to interact directly with people who have impairments, as this participant did in her work as a nanny for kids with special needs.

The third woman interviewed that had read some small parts of a pregnancy guide for a child development class in high school reported that what she read helped her develop a more positive perspective about potentially having a child with an impairment. Specifically, she conveyed, “[The pregnancy guide text] kind of taught us how it doesn’t mean you’re losing out really. It just means it’s a different lifestyle [the family is] gonna live.” After hearing these three viewpoints, it became apparent that the participants’ initial interaction with the information in pregnancy guides helped develop very different perspectives about potentially having a disabled child.

Reflections on language and meaning in pregnancy guide books

The substantive portion of the interviews involved the women in this study reading two passages of text drawn from two of the pregnancy guides analyzed during the content analysis stage of this dissertation research. After reading each passage, those involved in the study reflected on whether the information presented in the passage conveyed an overall positive, neutral, or negative emphasis concerning having a child with a disability. The women were also asked to provide reasons for why they expressed this feeling about the passage. Lastly, they had to provide a justification of the tone they felt was present in the passage based on specific language/terms the authors used to describe a disabled person. This final set of reflections about the language the authors used was highly significant. In some cases, women initially identified one of the passages as neutral, but after looking back at the passage and reassessing the specific language utilized, these participants noted the negative connotation that was clear in the authors' comments. Although the initial assessment questions included in the interviews produced a variety of responses and patterns, there was less variability in the responses women provided about the passages they read. Common themes were apparent in the participants' reflections and they are outlined here.

Perceptions of Discourse from "What to Expect When You're Expecting"

A common thread flowed through the comments from most of the women when they read the first passage presented to them from a pregnancy guidebook. Many women felt that it was obvious that the authors were postulating that a disabled child is not seen as "normal" and is, instead, problematic. This first passage was, thus, perceived by most women as providing a negative connotation towards the possibility of having a disabled child. Further, participants often noted that the apparent goal of the passage appeared to be to reassure expecting parents that their future child likely will not have an impairment. Participants felt this was an odd or inappropriate perspective for the authors to present because it was as if the authors assumed parents will automatically perceive a child with an impairment to be a negative outcome. Many women in this study did not feel this way about an impaired child, and so they commented on the inappropriateness of the authors' subjective judgements.

One illustration of a woman who indicated she felt the passage exuded a negative overtone relayed that:

> [It's] negative. The sentence that stood out to me was where it talked about '[Most women who have an abnormal result] go on to have a perfectly normal and healthy child,' so they are talking about 'normal,' as in what's perfect… So if you have a child that has some kind of 'abnormal problem,' then that's referring to it not being perfect, so that's not good… The 'normal' and 'abnormal' language referring to babies who are either diagnosed with having a disability or not having a disability- not having one means that they're normal, having one means that they're abnormal, whatever 'normal' may be… It's pretty subjective. I mean, there's no objective way to really define normal, it's just kind of what society thinks it is.

This participant not only focused in on specific terms and phrases in the language presented by the authors that she felt carried a negative connotation, but also emphasized an awareness of socially imposed ideas dictating what we, collectively, perceive is “normal.” She also points out that society’s perception of “normal” is subjective, just like the judgements posed by the authors in this pregnancy guide. This certainly seemed to continue the theme of some of the participants being aware of the social context of the construction of ideas.

A second participant in this study posited that there was a subjective, or “biased,” undertone to what was conveyed by the authors of this pregnancy guide, on top of also highlighting similar negative language as the above quote illustrated. Specifically, this participant noted:

> Oh, I think it’s negative. I think it’s trying to be neutral, but I don’t think it is. The second to last sentence is sort of a caveat. It says, ‘Most women who have an abnormal result… go on to have a perfectly,’ emphasis on ‘*perfectly* normal, and healthy child.’ That to me suggests that this is the preferred result… The word ‘normal’ takes on a level beyond within the normal curve; it means so much more than that to most people. ‘Perfectly’ and ‘normal’ are really the only words that throw me off, but they throw me off pretty hard. Oh, and ‘problem’… It’s so subtle, like it’s worded very intelligently, so I could have read that without even noticing the, I think, bias that’s in there.

In a more indirect way, a third woman made note of what she perceived to be a judgmental tone in this same passage when she underscored that it seemed that the author(s) were suggesting what they felt was “normal” and “desirable” to expecting parents. She articulated:

> I feel like it’s a bit negative. I think it gives a good attempt at being neutral, but… I guess the word ‘problem,’ that’s a word that makes it seem like that’s not something you want. I feel like they could have said a different word there… Overall, the passage, the bottom half, is makes me feel like that. ‘…most women who have [an abnormal result on their screening test] go on to be perfectly normal.’ I feel like they want that to be the case, and so you feel like that’s what you want. So, I guess it gives a little bit of a negative attitude because it gives you an idea that’s not what’s supposed to happen. It’s almost like it’s setting a standard… [What they express about a disabled person is that] it’s not normal, and that it’s not something that a mom would want to have.

A fourth woman expressed the sentiment that she thought several terms and phrases were problematic because they give a negative perspective toward having a child with a disability. She indicated clearly that she felt different, and less disparaging, terms could have been incorporated when she stated:

> I think it’s kind of negative. It uses words like ‘chromosomal problems’ and then there was another one, ‘it does not guarantee that your baby is normal’ and I think, personally, I don’t like the use of [the] word ‘normal’ cuz I don’t think anybody is ‘normal.’ I think we’re all different so… It says ‘chromosomal defect’ [and] ‘problems’ quite a few times and, well, I don’t like that… I feel like they could use different language.

Some women in this study honed in, specifically, on the authors’ emphasis on the distinction between babies that are either “normal” or “abnormal” was not acceptable because it positions those with a risk of impairment as inherently “problematic.” This was conveyed in one interview when the participant relayed:

> I think [it’s] negative because it repeatedly refers to the child having a problem and it immediately sets the tone of chromosomal disability as a problem. I also think that the whole part where it’s like ‘Well, you could have normal test results and still have a problematic baby or you could have problematic test results and still have a normal baby’… the whole ‘problematic’ versus ‘normal’ definitely puts chromosomal disability on a scale that is highly subjecting it to a negative view…

A second woman who honed in on this pattern when she discussed what she perceived was a negative emphasis by the authors provided a similar sentiment. She felt the language used implied the assumption that having a child with a risk of an impairment was negative, abnormal, and/or not desirable. Although this participant had initially labelled this passage as having a neutral tone, upon being asked to assess the use of language in the passage that discussed a disable person, she changed her classification of the passage to negative. Specifically, she remarked:

> I would say [it's] neutral just because they didn't really use any negative, I mean, at the same time… okay. [Pause] Maybe a little negative cuz it says, 'at the same time, a normal result does not guarantee that your baby is normal.' I mean, I guess that could kind of be construed as a little negative. Like, just because somebody has a little disability doesn't mean they're super abnormal… 'Perfectly normal and healthy child.' He can be healthy and still have a disability… Why is it not fine to have someone with a disability? So, [it's] kind of imposing the idea that you need to check or need to have this test done basically. I mean, I get precautionary measures, just so you kind of know what's going on, but I just feel like the way they're saying it is just a little strange. I think it would be better if they were to say 'we'll just have this test done just to make sure everything is going smoothly inside the womb.'

As with previous examples of this pattern, this participant indicated that she perceived the language used by the authors, and the overall tone/meaning of the passage, was negative and could/should have been discussed in a different, more neutral manner.

A third illustration of this theme was presented when a different woman in this study conveyed a similar concern when she stated:

> I'd say negative because it says 'abnormal.' It says 'abnormal' or versus 'normal' and 'healthy.' 'Defect.' [The language used to describe a disabled person indicates] that they're not normal, they're different than… Basically, they're not considered what normal is… They should just use better language.

Again, as was the case with many participants, this woman indicated that she felt the language was problematic in terms of the picture it painted, which set a negative tone concerning having a child at risk of a disability. Several women reported that they felt that the language used by the authors could/should have been different and many cited "condition" as a better term that could have been used in place of "defect" or "problem" to describe a disability.

The other major theme that was apparent among the many participants who felt that this first passage was negative centered on the pervasiveness of "worry" and, at the same time, "reassurance" they perceived as a goal of the authors' comments. This theme is illustrated well in a statement made by a woman who felt the passage served the purpose of invoking fear when the participant stated:

> [It's] negative. It just kind of stirs up emotions… [It is] evoking worry, definitely!... When describing the [prenatal] test, I don't think that the word 'normal' should be used even though, you know, I used it myself, but in [a professional setting], when giving someone feedback about a [prenatal] test, I… think they should use a better word.

The connection between worry and reassurance, seen as simultaneously appearing in the passage, was reported by a second respondent when she remarked:

> [A problem with the language is] ‘perfectly normal’… [and] maybe the word ‘problem’ instead of maybe ‘condition’ or something… [and] that [the impaired child] doesn’t fit the norm and then it implies that it would lead to problems?... I feel like it’s simultaneously trying to worry the mother, but then [be] reassuring?

A third woman indicated a similar sentiment, but articulated that the passage, itself, didn’t necessarily “create” a feeling of fear or worry, but it more so reinforced underlying worries she may have already had (if she were an expecting parent). Specifically, she noted:

> [It’s] kind of negative… because it’s so reassuring or trying to be reassuring, I think it kind of gives off a negative connotation… The meaning [of the language they use to describe a disabled person] kind of reinforces the whole ‘it’s going to be a negative experience’, so by reassuring [us], it’s like ‘we recognize that this is a negative experience so, therefore, we’re going to try to reassure you that by using all of this jargon about statistical likelihood…’ it would just kind of reinforce whatever fear I might have.

Regardless of whether women perceived the passage to create a sense of worry or the passage reinforcing existing fears, women in this study felt that the passage seemed to assert the assumption that having a child at risk of a disability was a negative experience. Additionally, several noted that the writing conveyed that expecting parents would be worried and it required reassurance for parents.

Although most respondents interpreted this first passage to be negative, several others indicated that they had difficulty selecting only one label that fit the entirety of the message in the selected text. They mentioned that the tone of the passage could vary depending on how a reader interprets different parts of the information offered in the text. For example, one woman relayed:

> I feel like they tried really hard to be neutral, but at the same time, they made it… a person reading this could jump to conclusions, like maybe they did have a test come back that [said] 'you have a 40 percent chance of having a child with Down Syndrome'… It seems kind of weird that they would even give out that information, honestly, because it is only a chance, and maybe that is good to have if you're planning to, ya know, prepare yourself… but you also might encourage someone, especially this early in a pregnancy, to abort, especially if something did come up and they didn't feel prepared. That could definitely be a problem, I mean you can't discriminate like that who you allow to be born. So, they tried hard to be neutral but I feel like the information they did give, someone could take and run with and make it negative. At the same time, the person could take it and make it positive, too [although it is probably less likely]…

Even though this woman seemed to indicate the passage could be interpreted in all three ways (positive, neutral, and negative), this participant tended to emphasize "negative" a bit more than the other descriptors. An additional indication of this came when the respondent discussed the language used to describe a disabled person when she stated:

> I think the word 'normal' is kind of interesting because it's kind of hard to say what's normal… It's kind of funny to jump to say that someone who may have a problem isn't normal. That's the biggest thing that jumps out to me.

Like many of the women who labeled the passage "negative," this participant honed in on the subjective nature of language that seemed to convey that the authors perceived disability to indicate a person is "abnormal."

In a similar vein, another woman expressed that she felt the passage could be interpreted in multiple ways. Additionally, she argued that parts of the passage could even be labeled "positive" because it might allow for parents to feel better prepared.

However, she also indicated an overall tone may have provided a negative feeling about disabled people. Specifically, she stated:

> I think it makes people a lot more paranoid than it needs to be because, obviously, [the prenatal tests] don't test if there's a chromosomal problem. It just tests if there's a likelihood of it. But I think it also, in some cases, might prepare a parent better, so it's not a complete shock. I think there's a lot in preparation for any kid, [but there is] especially with one that you have to take care of a little more… It really could be all three, [it] just depends… I'm going to have to say… [it would] be positive… I feel like [some] other things, it's a little negative. [The meaning that is being expressed about a disabled person is] that it is a problem, like they're saying 'abnormal,' and words such as 'abnormal,' and ya know they're saying, 'but your kid might not be perfectly normal,' so they're saying [there is] a negative connotation to it.

Thus, when reflecting on what the language conveyed about a disabled child, the participant conveyed she felt it had a negative feel, though the information could have served a practical purpose by providing parents with some insights about their child.

Although most respondents interpreted this first passage (or at least the overtone of the passage) to be negative, several others indicated that they felt it was neutral. Based on the pattern of responses from the participants that perceived the passage as neutral, however, they did not come to this conclusion based on the language used to describe a disabled person. Instead, these women understood a label of "negative" to mean that the passage clearly indicated a parent had received test results showing their infant was at risk of an impairment. In this case, it seemed that the participants may have also been under the impression that having a child with an impairment was, inherently, a negative experience. Thus, because the passage communicated that abnormal test results may provide a false reading and a child could still be born healthy, the passage was deemed “neutral.”

This theme among those who deemed the authors’ points to be neutral was conveyed clearly in this illustration from a participant:

> I think it [is] kind of neutral cuz it doesn’t really about having a child with a disability; it’s saying ‘hey, this test, it kind of gives you an idea’ but doesn’t really say ‘causes it’… It doesn’t really have like ‘disability,’ it says ‘chromosomal defect’ and [it’s] kind of more scientific, so it feels kind of more objective… scientific… It’s only about chromosomal, like they don’t tell you what it could mean, like Down Syndrome… So, I don’t know, you don’t really think about it because they’re not specific.

As indicated above, since the passage did not discuss specific impairments and because it discussed the likelihood of false positive results in prenatal testing, this participant felt it had a neutral tone. Thus, if the passage had included mention of one or more specific impairments or discussed test results that more definitively identified a disabling condition in the fetus, the passage would have had a more negative overtone.

Another example of a woman who perceived the passage to be neutral because the tests discussed in the passage are not able to clearly confirm that a disability is present in the unborn child was articulated when she stated:

> I say neutral because it’s saying that, really, even if it’s saying that your child could have some type of defective issue, that they also [might not] and that a lot of people, or women, who had that [abnormal result] on the screening turned out to have normal babies… They don’t really seem negative, as if there would actually be an issue. I feel like it’d maybe be a little more positive just because it kind of says that your child could have something wrong doesn’t mean it will, trying to make it seem like it might be okay.

This woman indicated in her reflections that because the passage seemed to reassure expecting parents that an abnormal result may not truly indicate a disability was present, then the passage may have a positive tone. This would indicate that the participant would feel that a passage with a negative tone would be one where it confirmed a high likelihood/reality of having a child with an impairment.

A final illustration from a woman that conveyed a similar stance came when the participant remarked:

> I feel like it's pretty neutral because it's saying [whether the child is born with an impairment or not] could go either way, no matter what the test results are… [The meaning of the actual terms describing potentially having a disabled child include] when it says 'abnormal,' just like when something's wrong with you, like unique. It says 'chromosomal problems'… I feel like it's saying something's wrong with you.

As was the case in the reflections of the two previous participants, it appeared that this woman relayed that because the text indicated that abnormal test results are not conclusive about ultimately having an impaired child, this woman felt the passage had a neutral tone. Additionally, there was some inconsistency in regard to how she labeled the passage, which was also noted by at least one other participant. This woman labeled the passage as more "neutral," but then articulated that the authors used negative language to describe a disabled person.

The participants' discussion of the first passage they were given to read and reflect upon revealed a common theme, where most women perceived the passage to possess a negative undertone. This was even the case among one of the participants who gave the label of “neutral” to the information in the passage, but then outlined ways in which it also carried a negative connotation toward disabled people. The other respondents who felt the passage was more neutral apparently perceived it that way because the passage indicated that abnormal test results don’t always lead to a disabled child. Therefore, if the “negative result” of having a child is not conclusively provided to parents through prenatal tests, then the information was “neutral.”

Perceptions of Discourse from “The Girlfriends’ Guide to Pregnancy”

While the reflections about the first passage provided seemed to indicate a fairly cohesive theme, the responses provided about the second passage followed one distinctive overall pattern: women felt it contained negative language and had a negative message. The only small caveat to this theme was that two participants who initially labeled the passage “positive,” only because they misread the strong language used by the author as conveying sarcasm. For example, in one specific part of the passage, the authors remarked: “…most agonizing of all, if the amnio tells us, God forbid, that our baby is genetically abnormal, we would have to decide whether to terminate the pregnancy.” Three women felt that there was no way the author was being literal, or was actually suggesting that parents may have to decide to abort their child if tests indicated a risk of impairment, so they took the message as sarcasm. They felt the perceived sarcasm was “positive” because they felt that the author was mocking or making fun of those who would consider aborting a child simply because of abnormal test results. The message provided by the author in the passage was perceived to be so unreal, or so negative, by the participants that they couldn't believe it was really being stated. Thus, they interpreted it in the only way that made sense to them- as sarcasm.

There was much repetition in the participants' responses that they felt conveyed the passage was negative. Namely, the women in this study consistently focused on the following terms and phrases as ones that provided a negative overtone: "God forbid that your baby is genetically abnormal, you would have to decide whether to terminate the pregnancy," "agonizing," "genetically abnormal," "the test itself harming the fetus or causing the miscarriage of a healthy fetus," "long needle," and "terrifying." Interestingly, some of the terms and phrases the participants identified as conferring a negative tone were ones that did not relate to disabled people but, instead, connected to aspects of a prenatal test, such as "long needle." However, some women noted that these terms acted as triggers for negative emotions and, when used in conjunction with information about children with potential impairments, the negative emotions may be transferred (or carried over to) that other topic. Further, some participants remarked that when the authors used many terms that all invoked negative emotions together in the passage, it felt like the authors tried to generate fear and worry among expectant parents.

One woman provided reflections that clearly illustrated the feeling that the second passage offered to participants carried a negative undertone, which is conveyed when she noted:

> [It's] negative. The first 'God Forbid' is quite strong and then, when it's talking about the third reason people are terrified of these amnios, they used the word 'agonizing' if the result is 'genetically abnormal.' [The meaning expressed in the language used to describe a disabled person is that] people do not want to have a disabled child… At the end, where it's talking about the possibility of 'deciding whether to terminate the pregnancy,' I thought that was odd… [an] extreme [reaction] for finding out that your baby [might] be abnormal.

A second participant took exception with similar passages and noted their negative tone, when she expressed:

> I feel like this one has a negative emphasis. The very last sentence says, 'The most agonizing of all'… and 'God forbid that the baby is genetically abnormal' and then they go on to say that they'd 'have to decide whether to terminate the pregnancy' given those things. It seems like that'd be a pretty negative [reaction for] whoever reads this… They think that [having a disabled child] is bad.

In a third interview, there was additional emphasis given to the negative language used by the authors when discussing the possibility of having a child with an impairment when another woman articulated:

> [It's] negative cuz it more [so] talks about the risks and how horrible it can be and talks about terminating the pregnancy, which I feel is all very negative… It's just really opinion-based; it's not fact-based… I mean, everyone has a right to their own opinion, so I can't really say that they're wrong, but… I feel like this could be a poor test and they're just saying everything that could go wrong with it instead of the benefits…

Similar to the woman in the previous interview, a fourth participant also commented on the emphasis given by the author that seemed one-sided in terms of how the author highlighted only negative outcomes and feelings toward potentially having abnormal test results. Before I could even read the entire question to the participant, asking if she felt the passage had a positive, neutral, or negative emphasis, the woman interrupted me and stated:

> Negative. Negative. I'm gonna bet [the women being described in the passage] got amnios. I don't think [amnios] are necessary; I think it's good to know and be prepared, but other than that, it causes a lot more harm… And the way that they say [laughing] 'God forbid that your baby is genetically abnormal'… I think having a kid with special needs isn't a bad thing or a good thing. I think it does cause a lot of positive things for the family that they are given to. I think they're making it very negative… They said 'we'd have to decide whether to terminate the pregnancy; they don't give an option… They just say: 'you should terminate the pregnancy,' they don't really give [many] options.

A fifth participant that found the second passage to have a negative overtone began her reflection with a remark about how the passage might have a positive tone. However, when she was asked to review the meaning conveyed about disabled people given the language the author used, she changed her mind about the overall message being conveyed. This was illustrated when she relayed:

> I guess I would say… positive? Because they're kind of like saying they don't want to take this test and… ahhh… I don't know. This one' hard because it's… It kind of makes me sad because, at the end, 'we're gonna have to decide whether to terminate the pregnancy' but they don't really say what kind of… I don't know how serious would this be? Like, why would you need to terminate it, I guess?... See, Down Syndrome doesn't seem that serious to me… There's been plenty of people who I've met who [have] Down Syndrome and have a perfectly normal, happy life. Like my grandfather's brother, Bob. He was born, in like the 30s… my great grandparents kept him [at home] and just raised him… he just died three years ago… so he had a really long life. It just doesn't seem like it's that serious, like why would you want to consider that?... Looking back, I'm thinking it's more negative.

While reading, a sixth woman looking over the second passage paused to ask, “This is from a book?” and when I clarified that “Yes, it is from a pregnancy guidebook,” she laughed and said, “That’s hilarious.” The reason she found this information in the book “funny” was articulated when she stated:

> [It’s] negative [because of] the pensive obligation in the last sentence, ‘…if the amnio tells us, God forbid, that our baby is genetically abnormal, we would HAVE to decide whether to terminate the pregnancy.’ Just the fact that that’s a given… If you’re thinking about whether to terminate a pregnancy… that’s obviously something this person is suggesting you wouldn’t want… [The meaning expressed in the language used to describe a disabled person] is it may or may not be worth bringing such a fetus to full term.

Three other participants clearly conveyed that they felt the second passage contained a negative quality and took a more critical approach when reflecting on the author’s points. A clear illustration of a participant that provided a blunt analysis, full of critical comments was seen when a seventh woman remarked:

> [It’s] negative. The language used… it’s just negative. Like, being ‘terrified of amnios’ and then ‘the needle hurting like a son-of-a-gun’ and then ‘genetic counselors and OB’s being obligated to tell people that there’s a small chance of harming the fetus,’ it’s just all bad news… This was just bad. It’s just scary… ‘God forbid’ and ‘having to decide whether to terminate the pregnancy.’ I think that’s very negative because it’s sending the message that, if you’re having an ‘abnormal child’, that you do have an increased option of terminating a pregnancy, like that’s something that you can consider. I don’t think that’s something that should be included. It’s just putting it in like it’s a horrible thing to have an abnormal child. Is this real? Like, is this really taken out of [a real pregnancy book]? Are you [sure]? Wow… Usually when you give/provide information to people, you write it professionally and make people a little more confident because this is definitely a difficult situation for some people and not for others if they’re not from working with someone with a disability. But I wouldn’t use this wording, this is horrible… Terminate my pregnancy? Don’t put that in my mind, that I should terminate my pregnancy if my child is not normal. That’s not okay. Wow, this is amazing… And people actually read it? [Laughing]

It was apparent that this participant was surprised at the way in which the information was presented in the passage and the specific language used by the author. Not only was she shocked about the way the points were conveyed by the author, but she was also concerned that the book was something that would be widely disseminated to the public.

On a similar note, an eighth woman noted the perceived lack of professionalism exhibited by the author in the this passage. Additionally, as was the case with reflections about the first passage, this participant took issue with the specific language used by the author and felt better terminology and phrasing could have been used. Specifically, she mentioned:

> [It's] negative, again, mainly [because of] the last sentence, it says, 'God forbid that our baby is genetically abnormal,' and then it says 'we would have to decide whether to terminate.' To me, it sounds like if you have a disabled person, or if the results tell you there's a high chance… it sounds like they want you to terminate the pregnancy and that, if you don't, your fetus will be severely abnormal and it will never be a healthy fetus… I'm just surprised this is in a pregnancy thing. [Laughing] This sounds like almost a journal article of someone analyzing it instead of a direct passage. I'm surprised that they even used 'son-of-a-gun' and 'God forbid' language like that. Their language choice is just awful.

As a person with learning disabilities, herself, and as a person with many close friends and colleagues with impairments, a ninth participant conveyed that she took the perceived negative sentiment of the author personally, and she remarked:

> It's definitely negative [because of] the line 'God forbid our baby is genetically abnormal' and the whole, 'we would have to decide to terminate the pregnancy' and 'the chance that [the] fetus could be harmed,' 'doing the test for this could cause miscarriage' and the words 'terrifying' or 'abnormal' or 'God forbid.' Words like 'long needle' can be triggering for people. 'Son-of-a-gun' is also another one… I think the way in which they talk about people with disabilities is really screwed up and I think it has a lot of ignorance in it… It's frustrating cuz I know people with disabilities. Or, how even if you didn't know a person directly with a disability, being an ass about it is still [not good].

Another interesting interpretation was expressed by 3 of the 15 participants who viewed the passage as adopting a sarcastic tone. Two of these participants also noted that they felt the author must have been making fun of those who see a possible disabled child as such a terrible thing because seeing a disabled child in a negative light did not seem like a real thing someone would include in a pregnancy guidebook. The first woman who identified a sarcastic tone in the passage remarked:

> This one’s I think, [pause] positive because they’re referring to, I guess, abnormalities as something we fear, but probably shouldn’t be feared as much as we do. Well [the author points out], especially the last sentence, it’s common for women, when they figure out that they’re having a baby with Down’s syndrome for example, they question whether to terminate the pregnancy. Which is an unfortunately reality, but I think that shouldn’t be really an option, so I’m glad that they’re kind of highlighting that. And I think they’re kind of saying that it shouldn’t really be something we should be so worried about. That having a child with Down Syndrome probably isn’t going to be the end of the world like most women might think that it would be. [I feel this way about the passage because] I guess sarcasm, [it’s] kind of sarcastic. I guess they’re making fun of people who make it such a big deal. For me, it’s kind of hard to tell whether it’s positive or negative, for one, because they’re using sarcasm, and it’s hard to figure out what their true point is. I can’t tell if they’re saying that amnios would be a good or bad thing to do.

A second participant initially felt it wasn’t possible for an author of a pregnancy guide to make literal statements that posited abnormal test results might lead to considering an abortion of a fetus with abnormalities, articulated:

> I think [it’s] positive, but they’re being, well… In the last phrase, for example, it’s ‘God forbid our baby is genetically abnormal.’ I feel like they’re being pretty sarcastic in that and they’re, I don’t know, they’re doing it in kind of a strong way, but they’re saying it’s in some way bad or evil to have a baby that has a disability… [The meaning expressed in the language to describe a disabled person is] well, again, in the sarcasm, I suppose. They’re kind of poking fun, in a fun way, of people that condemn people with disabilities. I don’t know if I agree with the way in which they’re saying it, but they’re not making it any secret that they disagree with that kind of perception… Okay, I’m starting to consider where it’s coming from and this is coming [from] a pregnancy guidebook, right? [Answer: yes] For [it] being from that, I don’t know how much sarcasm they’re going to use… I don’t know [because] if I wrote that, I definitely would not have put that in there; it seems a little bit stronger language than I would have said… I totally hate to switch my answers, but I… forgot that was coming from a guidebook.

After explaining to the participant that the passage was not meant to be sarcastic (i.e. in the larger context of the passage, the author was, literally, talking about a time when she had been pregnant and felt she had to consider abortion if the test results had been abnormal), the participant was very disappointed and angry to hear that. The woman indicated that she had, initially, felt there was no way that the author could have been literal with the discussion offered in the passage, and so she had understood it to be sarcastic. As mentioned in her reflections about the passage, the strong language used by the authors ended up helping her to understand that the passage likely did not have a sarcastic tone.

The previous participants were not the only one who were confused by the tone of the author in the second passage provided during the interviews. A third woman also thought the author must have been joking in her comments and, in a sense, exaggerating her sentiments in a sarcastic way. Specifically, she remarked:

> [It's] kind of negative just because it does bring up the termination of the pregnancy if the child was abnormal. [The meaning expressed in the language describing a disabled person involves] '…if the tests come back abnormal, then 'the termination of the pregnancy' is a big… not a big decision, but just on the table… This passage, I think it does have a negative sense for 'abnormality' but it's kind of also lighthearted because they use phrases like 'son-of-a-gun' or 'God forbid' and stuff like that in kind of a lighthearted, joking manner.

In the broader context of this passage in the pregnancy text, the author informed expecting mothers about how much an amnio (or, at least, the needle used during the test) hurt when she had it done. Also, she was speaking literally about concerns and thoughts she had about an amnio that was performed (and also reflected on her friends' experiences with the same issues). As mentioned previously, some participants either needed to have a larger section to read involving this passage to understand the tone the author took or could not accept the literal statements the author made.

Although the final group of participants also interpreted the second passage to possess a negative connotation, these women indicated a similar pattern to that noted about the first passage. Namely, three participants found the last passage seemed to try to invoke fear or worry in expecting mothers. This pattern was exemplified when one woman stated:

> [It's] kind of neutral… [The meaning expressed in the language used to describe a disabled person] is pretty negative. If you look at the last sentence where it says, 'and third, most agonizing'… 'if the amnio tells us, God forbid,' I think that's very strong language and I think that makes it very negative. Even like the last part 'whether to terminate the pregnancy.' I think it kind of speaks to the fear we have if we realized or someone, a professional told us, this is… the likelihood of your baby having this type of reality when they're born. I think it's very intense [and] it kind of just reinforces this fear that we may have.

Another woman seconded the sentiment that it appeared the author's points would likely be difficult for expecting mothers to hear and, even if doctors may be on hand to make them feel more comfortable with test results, the points made in the pregnancy guide may incite fear. She noted:

> [It’s] very negative because it says things like ‘God forbid your baby is genetically abnormal,’ like it’s something terrible. It points out that ‘this test could lead to a miscarriage’ and then it goes on to say ‘you could decide to terminate the pregnancy’ and that could be something that is very hard for someone to hear… It does [also] say ‘terrified,’ like if you know nothing about the tests, like when you’re talking to your doctor, you’re probably already going to be scared, even if your doctor is going to reassure you.

A final participant that commented on a perceived emphasis on worry present in the second passage also mentioned that she felt the author should have selected language that was more neutral about the topic at hand. Specifically, she stated:

> [It’s] negative because it’s saying ‘third, if the amnio tells us, God forbid, that our baby is genetically abnormal,’ it’s making it sound really obvious no one wants an abnormal baby, but it makes it sound like, really rude… And then it’s saying they ‘have to decide whether to terminate it,’ it’s not saying whether to keep it; it’s using more negative language. Along with the negativity, it just uses words like ‘terrified’ and ‘long needle’ to scare you or ‘it hurts like a son-of-a-gun,’ so those are all negative. It makes it sound a lot darker. It also says, ‘harming’ and ‘agonizing’… Especially with a pregnancy book, you don’t wanna scare the mom, especially if they are going to have a baby with some abnormal features. I would probably change all of those words, like you want to inform them without making it sound bad.

Whether the participants initially labelled the second passage as expressing a positive, neutral, or negative tone about having a child with a disability, their assessment of the language used by the authors in the passages led most women who were interviewed to identify the overall tone of the guidebook passage as negative. The women that maintained that the passage carried a more positive feel due to the author’s seeming sarcastic tone were angered when they realized the real message being conveyed by the author. Women in this study also articulated specific changes they felt could, and should, be made when discussing the possibility of having a disabled child. Specifically, women noted that language should be less “rude” or unprofessional, and that more positive and affirming language should be used to describe potentially having a child with an impairment. The women also expressed the idea that the guidebook needed to provide more information about options for expecting mothers, and that the author should try to avoid inciting fear in expecting parents.

CHAPTER VII

DISCUSSION

Introduction

Although women who are pregnant gain information about pregnancy through many sources, expecting mothers consistently cite that a primary resource from which they seek information is popular pregnancy guidebooks (Gardner 1995; Parrot and Condit 1996; Copelton 2006). One topic covered at length, woven throughout nearly every section of a pregnancy guidebook, is the topic of the possibility of having a child with an impairment. Given that these books are utilized to such a great extent by expectant mothers, it is important to identify ways in which pregnancy guides represent children with various conditions. Specifically, it is of consequence to understand the language, phrasing, and meaning suggested by the authors when discussing this topic. My analysis of three best-selling pregnancy guidebooks, and the interpretation of some passages from these texts by women who were interviewed, revealed distinctive patterns concerning the language used to describe the possibility of having a disabled child. Several conclusions are presented in this chapter from the findings gathered in this study.

Fear and Worry

One significant theme found, both in the pregnancy guides and in responses provided by women in interviews, was that of “worry,” “fear,” “danger,” and “panic” being connected to the possibility of having a child that has an impairment. In the pregnancy texts, worry was conveyed about all aspects of pregnancy, but there was a marked emphasis on fear over the health and development of the unborn child. The concern about health discussed by the authors centered on whether the unborn child could be harmed by chemicals, injuries, medication, prenatal testing, and any number of other, unnamed threats to a growing fetus. Specifically, the authors articulated fear about a fetus making it to term alive (i.e. the risk of miscarriage) and whether the child could suffer a health “consequence” which, in a vast majority of cases, meant an impairment of some kind. Whether it be a developmental delay, a physical “deformity,” or a genetic “abnormality,” the authors expressed that it is a fearful situation to be in to be a parent expecting a child.

Based on the context of the information where the fear of having a child with an “abnormality” or developmental condition appears, it seemed that the authors make an assumption about the lack of desirability of having such a child. The worry that they mention was likely connected to the lack of appeal connected to sickness or illness, which is typically associated with a person who has an impairment. Because a sickness or illness is branded as an, inherently, deviant state because it intrudes on a person’s ability to be a productive member of society, it is typically seen as an undesirable quality to possess (Parsons 1951; Freidson 1988). Much past research indicates that having a disability is typically equated with having a medical issue or “sickness” (Oliver 1990; Siebers 2001; Barnes, Oliver, and Barton 2002; Thomas 2002; Jaeger and Bowman 2005; Barnes and Mercer 2010). When the authors of the pregnancy guides discuss a child with a potential impairment as “worrisome” and something that is feared, having a disabled child is, then, cast in a negative light. Having fear and worry about a potential “health” outcome for a child does not impose a neutral or positive connotation toward that outcome. As mentioned by Simi Linton (1998:11), in *Claiming Disability,* “… the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy.” A similar trend occurred in the pregnancy guides, where the authors posited that it was fear-inducing to consider, even the small risk, that a child may be born with an impairment or “health” condition.

When authors of the pregnancy guides over-generalized fear and worry to all impairments that might be present in an unborn child, they left out discussion of the immense variability that exists among those who experience different types of conditions. By lumping all impairments as “worrisome” and “fearful” because they, supposedly, all lead to children who either have major health concerns or are not viable for life, the authors provide incomplete and incorrect information to expecting parents. The authors have the opportunity to provide a more accurate picture of the complexities related to some of the more common, specific conditions that often appear in newborns.

A striking finding from the responses provided by women who took part in interviews for this study, however, points to other possible meanings that women may associate with fear and worry related to a doctor indicating an unborn child may be at risk of having an impairment. The participants in this study revealed that health was not the main issue they felt would cause worry, or make them upset, if they were told their (hypothetical) unborn child was at risk of an impairment. Instead, they cited that the potential extra work/resources and fear of how others in society might treat them as the reasons they might be more upset than if they had been told they were having a (hypothetical) “healthy” child. In Chapter V, when discussing the content analysis findings, I articulated an issue present with the emphasis on fear and worry in the language used by authors. Namely, is the fear and worry developing among expecting parents because of how the authors emphasize worry in their books or is fear and worry something pregnant women already express and the authors are simply stressing an existing emotion? Based on what participants in the interviews mentioned, it appears fear and worry may already be present among those who are expecting. However, because the participants indicated they would be concerned about “abnormal test results” regarding the “health” of their child due to other reasons (like amount of resources), the *reason* for the fear and worry articulated by the authors may differ from what women indicated would actually cause their fear.

Another marked theme among the perspectives offered by interview participants became apparent when the women were asked to read through and reflect on the two passages taken from the pregnancy guides. It was noted by quite a few participants that they felt both passages they read had a strong emphasis on trying to provoke worry in the reader and/or provide reassurance about being told their child may have a slight risk for an impairment. Specifically, when reflecting on the first passage, 3 women indicated that it was clear that the authors felt that expectant mothers needed to be reassured about this possible negative outcome (i.e. having a child at risk of being impaired) and that the language/phrasing the authors used seemed to purposefully arouse fear. After reading and considering the second passage, 3 more participants indicated they felt there was a clear emphasis by the authors to incite worry, and also provide reassurance at the same time, as well. What the women noted, about the contexts of both passages, was that they felt the authors could/should have used a different tone when presenting this information.

Specifically, the women who noted the above-mentioned pattern remarked that the authors seemed to assume that women would find the prospect of having a disabled child to be “terrible” or that the child would not be wanted. Further, some participants even noted that they felt the authors were pushing the idea that having a “perfectly normal child” was the standard and that this is the reality the authors of the pregnancy guides want. This reflects well several points made by past researchers and theorists in the realm of both disability and deviancy studies. As noted previously, disability is deemed “out of the norm” and those who have impairments are often seen as a person with a sort of “tragic” short-coming or deficiency that will impact their ability to lead a full, worth-while life (Linton, 1998; Barnes and Mercer, 2003). This finding provides a specific context in which those who possess medical authority over a topic provide a subjective, one-sided perspective about the lives of those who are disabled, which helps reinforce the common sentiment that impairment is inherently an abnormal or “disrupted state” (Proctor 1995; Parens and Asch 2000; Goble 2003). Disability and health/illness scholars remind us that what is perceived to be “sickness,” and what is deemed “normal” or “abnormal,” is not inherent in an even or bodily characteristic. Instead, these perceptions are socially constructed and go through transitions as a society’s cultural and moral values transform (Becker 1963; Starr 1982; Brown 1995; Lorber and Moore 2002; Turner 2004; Joralemon 2006). The findings from the interviews in this study confirm that these theories apply in the interpretations of women reading the messages conveyed about having a potentially disabled child. Women expressed the same concerns, that the points articulated by the authors are not objective, but are subjective judgements about disabled people’s lives, as if their lives lead to only one inherent reality, namely: disappointment and tragedy, which expecting parents fear as a “terrible” outcome. Many complex realities exist in the lived experiences of those with impairments, but the authors do no discuss the variations in quality of life present among disabled people or the multitude of ways in which parents truly feel about the outcome of having an impaired child. Only one type of reaction is presented by authors, as if all impairments produce a “terrible” and poor-quality existence that parents *must* find abhorrent.

Impairment as Problematic and Abnormal

A prominent theme related to the above-mentioned pattern revolved around the authors of pregnancy guides using particular terms and phrases that posited impairment as a “chromosomal problem,” an “abnormality,” a “defect,” and as connoting “poor quality life.” This pattern was evident throughout the pregnancy guides analyzed in this study. Again, this theme is an illustration of the common assumption that a disabled person is perceived to be inherently “less than” those without “health” conditions (Proctor 1995; Parens and Asch 2000; Barnes and Mercer 2003; Goble 2003). Authors of the pregnancy advice books most clearly connected impairment to abnormalities and problems when they specifically paired terms like “abnormality” and “defect” with specific conditions, such as when Murkoff and Mazel (2008:60) state: “Increased fluid *may* indicate an increased risk of chromosomal abnormalities such as Down syndrome…” Another illustration of this was seen in a pregnancy guide when Iovine (2007:105) reported information about the topic of reasons for miscarriages and stated: “It is widely believed that about half of all miscarriages occur because the fetus was not normal.”

In many other places in the texts, several terms indicating a “problem” were paired within the same sentence with the term “disability,” “impairment,” or with the specific name of an impairment. With the use of this strong language, and by inundating the reader with these pairings so consistently throughout the texts, the message conveyed was clear: children with impairments are abnormal, defective, and a problem.

Another clear indication of a negative emphasis placed on the possibility of having a child with an impairment was apparent when authors of the guidebooks discussed the termination of pregnancies when a "problem" was identified. For example, Harms and Wick (2011:297) posited that parents need to "make decisions" if their fetus might be at risk of an impairment when they mentioned: "Prospective parents who are worried about possible genetic disorders… can undergo genetic screening… With this information, potential parents can consider what the risk is of having a child with a genetic disease and make decisions accordingly." A similar suggestive statement was made by Iovine (2007:91) when she remarked, "…if the amnio tells us, God forbid, that her baby is genetically abnormal, we would have to decide whether to terminate the pregnancy." These kinds of statements found among the pregnancy guides reinforces the already established sentiment conveyed by authors of the pregnancy guides that children with a risk of impairment are not desirable. Indeed, the authors indicated in their statements that these children are perceived to be so terrible, that parents *have to* made decisions about whether the infant is worthy of life or not.

This pattern relates well to the previous theme noted above concerning the emphasis by medical authorities that disability is perceived to be out of the norm and a state that is not deemed to be desirable, thus it is feared. When pregnancy guidebooks conveyed information in this way, we see support for the idea that media does not simply relay “factual” portrayals of social phenomena, but we receive the writers’ subjective perspective and beliefs about social life (Lee and Bristow 2012:508). Other past research and theoretical analyses by disability studies scholars indicate why such statements cannot be seen as objective is seen when Thomas (2002:49) argued, “…all social phenomena, including disability and impairment, should be understood to be woven through, and out of, cultural ideas and discursive practices: there is no ‘reality’ independent of ideas concerning it.” Much like the messages conveyed via numerous other sources of mass media, information provided by those afforded authority who write pregnancy guidebooks, are often based on subjective perspectives about people and their lives (Lee and Bristow 2012).

Women included in the interview portion of this study relayed a similar emphasis on the social construction of ideas about what is “normal” versus “abnormal” when they reflected on the passages they read. Specifically, several women noted that they perceived that the authors were setting the stage for what the authors felt was a “normal” outcome versus an “abnormal” result for pregnancy. Some women in the study felt that the language used was not in good taste and better terms could/should have been used when referencing a fetus with a potential disability. For example, participants felt that the authors using the phrasing “perfectly normal and healthy child” helped indicate that the authors conveyed a negative tone about potentially having a disabled child. This is because the women perceived that the authors were conferring that if a child had a risk of an impairment, they were not “normal” or “healthy.”

A couple of participants also mentioned that they were bothered by the fact that the authors presented the “option” or “directive” of “having to” decide whether to terminate a pregnancy where a fetus might be at risk of a health condition. They felt that was either inappropriate or the authors should have presented additional information about other possible options at that same juncture. After reading the second passage that contained this emphasis on “having to” decide to terminate a pregnancy if an unborn child may have a risk of impairment, several participants mistook the message by the author as sarcasm because the information presented took on such a negative connotation. These women, literally, had to try to reframe the information presented so they could make sense of it, because they could not conceive of a person giving pregnancy advice in a published book as taking that negative of a stance. After hearing that sarcasm was not intended by the authors in that statement, these participants were shocked at the gall of the author to make remarks that indicated that the risk of a child having an impairment was so terrible that the parent(s) would have to consider an abortion.

Further, women reported that the information provided in the language and phrasing used by the authors of the pregnancy guides conveyed messages that were clearly lacking objectivity. For example, one women specifically remarked they felt there was a “biased” tone when the authors discussed the possibility of an unborn child having an impairment as an “abnormal” and undesirable result. Another respondent pointed out that there is really no way to define what is “normal” because that is socially determined. The awareness displayed by the women who articulated these points conveyed they have an understanding of the ways in which social processes are at play in determining what is seen as “normal” and “abnormal.”

Additionally, the reflections noted above indicated a specific challenge to authoritative statements made by those who claim medical authority (i.e. the authors of the pregnancy guides analyzed in this study). The awareness displayed by the participants in this study posed a challenge to sentiments expressed by several social scientists who have argued that knowledge produced by the field of medicine is often accepted, and goes unchallenged, because people tend to instill faith that science informs them of “truths” about everyday life (Webster 1991; Lorber and Moore 2002). The responses by these women also contested an assertion by Arksey (1998) that those afforded authority in medicine are typically not questioned in their ability to be objective and value-free in the information they present to patients (or others).

Although a majority of women did not highlight issues with the passages they read concerning the topic of whether the information appeared subjective or judgmental, the fact that some women did broach this topic indicates that, perhaps, not all people always perceive medical professionals as fully objective. Instead, these reflections by the participants may provide substance to an argument posited by Markens, Browner, and Preloran (2010) that patient/doctor interactions often involve a patient-centered approach where patients have the ability to exercise agency by using information from medical professionals in making their decisions. As indicated by these few participants who noted the subjectivity they felt was apparent in the authors' dialogue, a patient (or member of the audience reading a pregnancy guidebook) can take information from a person who offers authoritative advice and interpret it in their own way. These findings help provide support for an argument I presented at the beginning of this dissertation. At this start of this research, I projected that a combination of approaches would be taken by the audience when they read and processed the information presented by the authors of the pregnancy guides. Based on the reflections of the women in this study and the divergent paths participants took in reflecting on the passages, their responses provide support for one of my hypotheses.

Lack of Impairment Equated with Health

Bodily states that were not previously thought of as medical issues, such as physical impairments, have become increasingly medicalized in the past century (Zola 1972; Conrad and Schneider 1992; Goble 2003; Conrad 2007). This indicates that medical professionals have successfully made the case that disabilities, for example, should be considered a matter of health. Under this premise, if a person has an impairment, they may be considered "unhealthy." As articulated by Simi Linton (1998:11) in *Claiming Disability,* "…the medicalization of disability casts human variation as deviance form the norm, as pathological condition…" As noted by these medicalization and disability studies scholars, authors of pregnancy guidebooks expressed the medicalization of disability as a “health” condition consistently throughout the advice books they wrote. Their dialogue positions disability as equal to a person who is lacking “health” and helps sustain the momentum of the process of medicalizing disability.

The ultimate goal of the majority of concern, worry, warnings, precautions, preparations, preconception care, and prenatal screenings that authors of the pregnancy guides discuss is to help ensure women have a “healthy” child. According to these texts, having a “healthy” child meant that the child did not have “defects,” “abnormalities,” or “health complications.” The authors expressed that there was concern over whether the “baby was born healthy,” “genetic health,” and having a “healthy baby.” The language use and phrasing on the part of the authors helped reiterate the point that a possible impairment in an unborn child is seen as an abnormal deviation that indicates ill health. Although most women interviewed in this study did not comment on the specific phrasing used to convey the high likelihood that women would have a “perfectly normal and healthy child,” some participants did draw attention to this phrasing. Specifically, some women remarked that just because a child might have an impairment, does not mean the child is “unhealthy.” During a majority of the interviews, however, most women indicated that their initial perceptions of being told they were having a (hypothetical) “healthy” child would mean that it did not have any medical conditions or disabilities. A child that had normal “physical functioning” was also emphasized by respondents as a sign that the fetus was "healthy." Thus, most of the interview participants indicated agreement with the emphasis noted by the authors of the pregnancy guidebooks, namely that a "healthy" child is one that does not have any conditions or impairments.

On a related note, the content analysis of pregnancy guidebooks in this study also revealed that technology, in the form of prenatal testing, is key in identifying what fetuses are "healthy" and "unhealthy." Authors of pregnancy books often cited that these tests can assess the health of the unborn child. For example, Harms and Wick (2011:305), in *Mayo Clinic Guide to a Healthy Pregnancy,* conveyed, "Whatever the reason [you are offered prenatal screening], certain tests can help determine the health of your baby while he or she is still in your womb. These are called prenatal tests." As noted by past scholars conducting research and developing theory in the sociology of the body, new technologies make "risky" fetuses "hyper visible." With the ability to view and control bodies through an increased emphasis on prenatal and genetic screening, bodies with impairments are being exposed to a negative kind of "hypervisibility" (Casper and Moore 2009; Rothman 2010) that are likely to impact impaired people in life-altering ways. Prenatal screening is seen by many disability scholars, and those researching the impact of new health technologies, as a new means of practicing eugenics (Davis 1995; Cunningham-Burley and Boulton 2000; Kerr and Shakespeare 2000). Not only do new prenatal screenings allow for "abnormal" bodies to be identified, but they help increase the pressure expecting parents feel to be “responsible” and try to prevent having a child with an impairment (Pollitt 2003).

Of course, the authors of the pregnancy guides do not label prenatal screenings as proponents of eugenics, nor do they use direct language that outright tells parents to abort a fetus that may appear to have an “abnormality” seen through a pregnancy screening. However, the authors often do present a directive, or at least suggestion, that parents who receive “abnormal” test results can use these results as a way to make “tough” decisions about whether to continue on with a pregnancy where the unborn child may be at risk of an impairment. It is important to note, as well, that many participants also drew attention to this part of the authors’ comments when they reflected on passages from the pregnancy guides. As noted above, many women highlighted that they felt the authors’ language and phrasing about the unfortunate “need to have to decide whether to terminate the pregnancy” if abnormal results were found, were seen as carrying a clearly negative tone. Many women remarked that they did not feel that this language was appropriate or neutral enough, and that the conversation should have also included mention of other options parents could/should consider.

Impairment as Related to, and Handled by, Medical Professionals

Many researchers and theorists in disability studies articulate that the medical model of disability is central to the viewpoints of most medical professionals. The medical model is a perspective that emphasizes a person's impairment, in their physical body, as the "problem" that needs to be "fixed" (Oliver 1990; Siebers 2001; Barnes, Oliver, and Barton 2002; Thomas 2002; Jaeger and Bowman 2005; Barnes and Mercer 2010). This model ignores the impact of social barriers, such as structural barriers or prejudicial social attitudes, as disabling for an impaired person. The authors of the pregnancy guides in this research thrive on the medical model of disability. Throughout the guidebooks, the authors posit that disability is related to medicine and health, and is something that is surveilled and "handled" by medical professionals.

It is consistently reiterated in the pregnancy texts that medical experts are needed by expecting mothers in order to administer tests, interpret the results, and discuss options of what to do in regard to the health of the mother and unborn child. The health of the child is portrayed as hanging in the balance and trained professionals are required in order to boost the chances of the unborn child being "healthy." As mentioned by Murkoff and Mazel (2008:125): "Women who see a practitioner regularly during pregnancy have healthier babies, and they are less likely to deliver prematurely and to have other serious pregnancy-related problems." When discussing the many possible "health" risks a fetus may encounter, authors often use the phrase "ask your practitioner" or "ask your genetic counselor", and pose the question "what can you and your practitioner do?” (Harms and Wick 2011:32; Murkoff and Mazel 2008:64; Iovine 2007:90). In addition, it was asserted by the authors of the guidebooks that medical experts and their expertise are needed at all stages of the pregnancy to provide the best “health” outcome for the child, and they are even needed for consultation prior to conception. This message conveyed in the pregnancy guides provided ample indication that the medical model of disability was relied upon by the authors in the way that they perceived impairment. The body is asserted to be the site of the “problem” and every effort should be made to identify and prevent/fix the issue. Further, disability falls within the realm of medicine- this is the location where it should be assessed and treated.

In the final chapter, I outline several key implications of my findings that provide suggestions for helpful revisions to current dialogue about pregnancy and the “health” of an unborn child. I also outline in the final chapter ideas for future research.

CHAPTER VIII

CONCLUSIONS

Summary

The medicalization of pregnancy, tying it effectively to the world of medicine, has successfully transpired since the early to mid-twentieth century (Abel and Browner 1998; Georges and Mitchell 2000; Armstrong 2003; Ehrenreich and English 2005; Conrad 2007). In modern day, when American women become pregnant and as they progress through the stages of pregnancy, it is widely accepted/expected that women consult with medical professionals. These consultations often take the form of face-to-face interactions, but also include women being advised to read pregnancy guidebooks in order to garner additional guidance and help from authoritative professionals on the subject of pregnancy and childbirth. Indeed, although expecting mothers gather information about pregnancy through a variety of sources, they consistently refer to popular pregnancy guidebooks as a primary source of information (Gardner 1995; Parrot and Condit 1996; Copelton 2006).

One key area of discussion that permeates pregnancy texts concerns the goal to have a “healthy” child and issues involving fetuses at risk of impairment. Because of these trends in regard to seeing pregnancy as a health event that requires medical expertise and intervention, along with the reliance on pregnancy guides as key sources of information for pregnant women, an analysis of the perspectives offered in the pregnancy texts was significant. It was also of importance to assess the ways in which authors of these texts present the desirability of having a “healthy” child in comparison to one that may have an impairment. This was imperative to understand given that expectant parents encounter the authors’ perspectives about what may “need” to be done in the face of being informed that the unborn child has a risk of impairment. Specifically, life and death decisions may be made by expecting parents based on the information they gather from medical professionals, which includes material found in pregnancy guidebooks. Therefore, the aim of this study was to examine the language and phrasing used by authors of pregnancy guides that portray children who are “at risk” of being “unhealthy” in order to identify what type of perspective is conveyed by the authoritative experts who author the texts.

In this research, impairment was understood by the researcher to be a state that is not, inherently, disabling or limiting in regard to the possibilities for one’s life. Impairment was perceived to be a natural form of variation found in the genetic make-up of human beings. This perspective came, in large part, from reflections on much past research that has indicated that meanings associated with disability are socially constructed and imbued with connotations depending on cultural values, social norms and deviancy, and morality (Starr 1982; Brown 1995; Lorber and Moore 2002; Barnes and Mercer 2003; Turner 2004; Joralemon 2006). Past research has shed light on the significance, and context, of perspectives offered to expectant parents by medical professionals in face-to-face interactions concerning the topic of a fetus at risk of impairment. However, few studies examined the perspectives of those seen as pregnancy experts in pregnancy literature that conveyed information about the possibility of having a disabled child.

In this research, I was especially interested in exploring the representation of the connotation and context presented about a potentially “unhealthy” child. I wanted to identify the level of desirability the authors connected to the reality that a child might be at risk of an impairment. Therefore, the key focus of this research was to assess the language and phrasing used by authors of the pregnancy guides when discussing this topic. In an attempt to gain an additional layer of insight, I conducted interviews with women of child-bearing age. The women who participated in this study provided reflections about their own interpretations of the dialogue presented in pregnancy guides that were compared to the findings of my own analysis of the texts.

Specifically, a qualitative content analysis was performed on 3 pregnancy guidebooks that were identified as consistently prominent among the top best-selling pregnancy texts in the nation. Utilizing these particular qualitative method permitted the researcher to complete an exploratory study that honed in on the precise language and context used by pregnancy experts when they converse about the possible “health” of a fetus. For the content analysis phase of this research, I analyzed a total of 1322 pages located within the 3 pregnancy guides selected for this study. All language and context on each page was assessed in regard to whether it was related to the topic of the “health” of an unborn child and what the underlying meaning was of the specific terms and phrasing used. Further, the interviews conducted as part of this study allowed for an additional lens with which to view and interpret the language and meaning presented in the pregnancy texts about the topic at hand. The reflections and responses provided by the 15 participants included in this study provided further insight about the language and context provided by the authors of the texts. Both methodologies used were essential in painting a picture of the context of information offered by pregnancy experts, providing more clarity than one methodology, alone, could have produced. The utilization of both of these methodologies suggests that future qualitative research about this topic would be fruitful. Specific areas of future research that are needed are outlined later in this chapter.

Due to the use of two different methodologies in this study, the analysis of data was presented in two different findings chapters. First, Chapter V outlined the themes regarding the use of particular language and phrasing that contextualized discussion of the broad topic of potentially having a child at risk of being “unhealthy” revealed during the content analysis phase of this investigation. Specifically, I identified that four distinctive themes were not only present given the topic at hand, but the themes were emphasized heavily with consistent language that carried a clear tone about the desirability of having a child at risk of an impairment. Chapter VI examined a secondary source of interpretation of passages in the guidebooks by gathering responses from interview participants who reflected on the message conveyed by authors about the topic of potentially having a disabled child. The findings garnered from the participants in this study demonstrated a great deal of consistency with the findings reported from the content analysis, with some additional insights revealed. Chapter VII then presented discussion of key findings from both phases of this study, along with a presentation of how these findings connect to past studies.

Contributions to Existing Literature

This research examining the discussion provided about fetuses at risk of impairment in pregnancy guide texts uncovered distinct patterns of language that portrayed having an impaired child as a negative outcome. Overall, the language used by authors examined in the content analysis included terms that presented a child with a possible impairment as “abnormal,” “worrisome,” an undesirable “health” state, and a state that needs to be attended to by medical professionals. These findings are similar to what other authors have concluded concerning a negative connotation often portrayed in discourse about the possibility of having an impaired child (Pernick 1996; Parens and Asch 2000; Goble 2003; Pollitt 2003). A contribution of this study to existing literature is the analysis of discourse about having an impaired child as it is presented in pregnancy guidebooks, specifically.

Further, these findings provide additional support for the persistence of the medical model of disability present among medical professionals when they perceive of and discuss those with impairments. Namely, this study reports similar findings to past research that uncovered a heavy reliance by medical professionals on the perspective that disability is a physical “health” issue that needs to be “fixed” and attended to by medical professionals (Oliver 1990; Siebers 2001; Barnes, Oliver, and Barton 2002; Thomas 2002; Jaeger and Bowman 2005; Barnes and Mercer 2010). In this study, a strong emphasis was found to be placed on the “feared” test result that indicated an “abnormality” may be at risk in an unborn child, which may pose “health” issues. And, because the worrisome results and abnormal outcome may be connected to health complications, medical professionals should be consulted and their guidance was necessary to ensure the best, “healthiest” outcome possible. When emphases like these are included in discourse provided by medical professionals, the presence of the medical model is reconfirmed. In particular, this study revealed that this additional source of communication (i.e. pregnancy guidebooks) provided another context by which the medical model of disability could be reinforced.

At the same time that the analysis of discourse in pregnancy guides confirmed continued reliance upon the medical model of disability, it also provided support for other authors who have documented the history of medicalizing disability (Zola 1972; Conrad and Schneider 1992; Goble 2003; Conrad 2007). The continued emphasis on disability being equated with a medical, or “health” condition, was displayed in numerous sections of all of the pregnancy guides examined. In some places, authors used an emphasis on avoiding “health risks” in the fetus by consulting with medical professionals (in the form of doctors, OB/GYNs, and other specialists) to ensure the best “health” for the child. As remarked by a participant during one interview, the use of language implying “health” in place of “a child free of impairments” was so subtle, but it was still there. Potential readers of these pregnancy guides are presented with this type of emphasis consistently in the texts and it has become so common to consider a lack of impairments as equal to “healthy” that it seems normal, as if the medicalization of disability has always been in place.

When authors of the pregnancy advice books discussed disability as equal to an ill state, they positioned impairment as something that was not desired and, thus, was feared as an outcome. Terms such as “worry,” “fear,” and “panic” were frequently used to frame the emotional response authors expected a pregnant woman to have as a reaction to being informed her fetus was at risk of an impairment. Their discussion of this “fear” was typically centered on the topic of the lack of desirability to have a disabled child. This finding related well to a past author’s assertions that when disability is seen as something akin to a “pathological condition, as deficit… and personal tragedy,” it invokes a negative association with the outcome of a child that may end up having an impairment (Linton 1998:11). This past literature specifically made the connection between medicalizing disability, and causing it to be seen as an “ill” or disordered state, as the key factor that would lead to a negative association or fear being paired with having a disabled child. However, findings from the interviews conducted elucidated that the fear and worry women associated with possibly having an impaired child was more so related to concern about how others in society would treat their child and/or about not having enough resources to adequately provide care for the child. In addition, participants noted that a source of anxiety about having an impaired child is not knowing what resources are available, not having specific insights into the particular condition their child has, etc. Uncovering this perspective from many of the participants during interviews was significant and provided useful insights that will be discussed in a later section involving implications for possible changes in the discussion provided in pregnancy guidebooks.

Another significant finding from this study was the emphasis provided by the guidebooks on an impaired child being seen as “abnormal,” “out of the norm,” and as “defective.” Along with these specific terms used, the authors of the books sometimes denoted quality of life assessments of the fetus that may have an impairment that provided sweeping negative generalizations about the perceived worthiness of these infants for life, itself. For example, when Iovine (2007:91) stated, “…if the amnio tells us, God forbid, that her baby is genetically abnormal, we would have to decide whether to terminate the pregnancy,” she expressed that not only would the potentially impaired infant be undesirable, but women would “have to” decide whether or not to keep it. Participants in this study also commented on their perception that this information carried a negative connotation and should not have indicated that parents “have to” decide whether to continue with the pregnancy, just because the fetus was at risk of an impairment.

The theme found during the content analysis of the pregnancy guides provided support for past research that there is a common assumption often relied upon; namely, one that regards a disabled person as inherently less than those who are deemed "healthy" (Proctor 1995; Parens and Asch 2000; Barnes and Mercer 2003; Goble 2003). In describing an unborn child with a possible impairment as "abnormal" and "defective," the authors conveyed that they perceived a disabled person as "less than" a person who is "healthy." Many participants in this study, however, took exception with the comments noted by authors about the perceived "abnormality" that disabled people supposedly embodied. Women in this study often took a perspective similar to what has been noted by disability studies scholars. In particular, the respondents indicated they felt the authors' perspectives were biased at times when they indicated an impaired person was "abnormal" or "defective." The participants' comments reflected assertions by past authors who have indicated that what is deemed to be "abnormal" is subjective and it changes over time (Starr 1982; Brown 1995; Lorber and Moore 2002; Turner 2004).

Thus, some of the women in this study did not passively accept the perspective offered by pregnancy experts who wrote the guidebooks, but they interpreted the information to lack objectivity and so they rejected part of its message. When several women demonstrated a critical view of the information in the pregnancy guides, they presented a challenge to past literature that proposed that those deemed to have authoritative knowledge about a subject are typically not questioned in their ability to be objective by their patient/audience (Arksey 1998). Instead, these participants confirmed findings from more recent research that found that interactions between doctors and their patients are not one-sided, where doctors give information and dictates and patients simply follow the doctor’s directions. Previous research highlights ways in which medical interactions between a doctor and patient often involve a patient-centered approach, where patients have (and exercise) the ability to use information as they deem appropriate from medical professionals (Markens et al. 2010). Essentially, they have argued that a patient is not a passive recipient of a doctor’s expert advice; the patient still receives information from a doctor, but they ultimately decide what to accept and what to incorporate into their decisions. When several participants commented on the fact that they perceived the authors’ comments were subjective and should have been stated differently, it was clear that an audience member is not merely a passive sponge for the information they receive, but they can be agential in processing and making use of the information presented.

Implications of this Research

There are three major implications that surface from the findings in this study. First, the specific language and phrasing used by authors of pregnancy texts needs to be modified in order to convey a more neutral tone about the possibility of having an impaired child. Not only did the content analysis in this study find that negative language is used consistently in conjunction with an at-risk fetus, but interview participants noted the pattern, as well. Many of the participants, at several times during the interviews, asserted that the language used by the authors is unnecessarily negative. Indeed, several of the women in the study said it was, specifically, “awful” or that they couldn’t believe such statements were being made by professionals writing a pregnancy book. A suggestion made by some of the participants was to use other terminology, such as “condition,” in place of “abnormality” or “defect.” In addition, another participant made the specific suggestion that authors could state something similar to: “We’ll just have this test done just to make sure everything is going smoothly inside the womb,” instead of emphasizing statements like: “…most women go on to have a perfectly normal and healthy child.” Several women had commented that they did not like the imposition of the idea that there is only one idea of what is “normal.” This reflected conclusions I found after the content analysis, as well, because the “normal” versus “abnormal” language implied “healthy” children were desirable and “normal,” while disabled children were perceived to be “unhealthy” and not desirable. Some women articulated that they would appreciate more objective, or professionally presented, information about available testing and the meaning of the results in order to be more aware and prepared, without the negative perception conveyed about an unborn child potentially at risk of an impairment.

Additionally, the authors of pregnancy guides need to provide more nuanced discussion of particular impairments and more information about the average, or range, of impact it may have on an impaired child’s life. The current discussion provided by authors of the pregnancy guides placed too much emphasis on grouping all impairments together, as if all impairments lead to the same realities. Women included as participants in the interviews conducted also did not include many comments about the lack of presentation of information about particular impairments. Only two participants wondered out loud about which impairments are identified through prenatal testing when authors used over-generalized statements about the testing checking for “chromosomal defects.” However, the majority of women interviewed did not express concern or questions about the lack of detailed information provided by the authors about the topic of outcomes for those at risk of particular conditions. This indicated that, for the most part, the interview participants adopted the dichotomous conceptualization of those who are “healthy” versus “unhealthy” in the way it was presented by the authors of the texts. Specifically, this demonstrated that there was a lack of concern expressed by participants about the lack of nuanced discussion provided by the authors that posited all of those with impairments as essentially experiencing the same negative outcome: a low quality, undesirable life. If authors of the pregnancy guides took a different approach to presenting information about potential conditions found among newborn children, perhaps they could assist expecting parents to consider impairments in their particular context, rather than as inherently leading to a poor quality of life simply because it is an impairment.

The authors of pregnancy guides have seemingly compiled information about pregnancy and childbirth in order to help women navigate pregnancy, but they are missing out on a crucial opportunity to provide some needed information to women. Specifically, when participants were asked what it would mean to them to be told their (hypothetical) unborn child was at risk for an impairment, they mentioned that they would do research and “get ready” for the child. In particular, they indicated they would research the specific condition their child might have, resources that are available for the child or family to help with their care, etc. Authors of pregnancy guidebooks could easily include some of these kinds of resources, such as websites that help expecting parents get started finding information about a specific condition in case it is needed, but this was not emphasized in the pregnancy texts. Indeed, there was only one mention by Murkhoff (2008:522) in one place, in *What to Expect When You’re Expecting,* of a resource available to help women with epilepsy have the healthiest pregnancy possible. The organization and phone number provided were not even there to help provide a resource of information for parents who may have a child with an impairment, such as epilepsy, but to help someone who already has an impairment develop a preconception plan. There is ample opportunity throughout the pregnancy guides to provide women with what the participants in this study said would have been the first thing they sought out when told their fetus might have an impairment. Fourteen of the 15 women interviewed failed to mention that they would be interested in aborting a child that was at risk of an impairment, yet that is what the pregnancy guides typically conveyed was *the* option to consider. In fact, some participants even specified in their reflections that they did not appreciate this emphasis on thinking about terminating the pregnancy because they felt that was sort of an extreme measure to take. The authors of pregnancy guides could focus more on supplying information about options and resources to expecting parents in a more neutral way, rather than offering the current sentiments they do, such as “having to decide whether to terminate the pregnancy” if a child may be impaired.

Third, the findings from this research also presented a need for a different approach when framing the discussion of disability as equal to a lack of “health.” The pregnancy guides in this sample contained a heavy emphasis on “fear,” “danger,” and “caution” surrounding the possibility of a fetus having an impairment, or it being “unhealthy.” Women in the study also expressed fear and worry about being told their (hypothetical) child was at risk of an impairment, but mostly for different reasons that those articulated by the authors. Also, women who were interviewed mentioned that they felt the books appeared to be trying to scare expectant mothers, rather than provide straight-forward information about a topic. By using specific terms like “fear,” “terrified,” “danger,” and “worry” with so much repetition throughout the texts, the authors seemed to implant and/or reinforce these emotions in women’s minds.

One worrisome pattern that is perpetuated with an emphasis on using this type of language is simplistic, dichotomous perceptions about health and illness. The pregnancy guides help to reinforce the mindset that a person can only be either “healthy” or “unhealthy,” as if there is no gray area in between. This pattern is problematic due to the impact it may have on the level of fear parents may have who read these books. This relates back to my points about the issue with authors frequently referring to a non-impaired fetus as “healthy” and “normal,” and an at-risk fetus as lacking “health” and being labelled “abnormal.” Does one genetic variation make a person abnormal and lacking health? Does this, perhaps, affect the ways in which expecting parents perceive the overall condition, health, and quality of life for their unborn child in a negative way? Using poor language choice that places an unborn child into one of only two possible categories may induce more fear and worry in expectant parents than what was already present before encountering the pregnancy text. Given the discussion of fear and danger leading to only a positive, healthy outcome or a negative, unhealthy outcome can lead to expecting parents that are terrified of how every action they take will impact their unborn child. With the context of information in the pregnancy guides about this topic, a parent's actions and what they experience while pregnant can only produce one of two possible realities: a healthy child or an impaired child.

Limitations of this Research

This study had some limitations that need to be discussed. First, the content analysis phase of this research included an examination of only 3 best-selling pregnancy guides. Also, as there are no previous studies to draw upon that provide an analysis of additional current pregnancy texts, or past editions of pregnancy books, this study can only provide a snapshot in time of what is discussed and how it is presented. Second, it would have likely have been helpful to confirm (or disconfirm) themes found in the content analysis by including a second researcher in the interpretation and coding of the data collected. Although, it was beneficial including a sample of women who could be a potential audience of the pregnancy guidebooks in the interview phase of this study because of the additional insight gained. The insight gained was still limited, though, because of the small sample of women interviewed and they only reflected and commented on meanings they found in two small passages of text. A third limitation that is key to present is that this study was completed utilizing a specific perspective, namely a social constructionist lens. This study may have revealed additional insights if a different perspective, or theoretical orientation, had been applied. Future research may assist in providing an analysis of other facets of implications of the findings of this study if additional analyses are performed on the content of pregnancy texts.

A final limitation of this study that is significant to discuss was the characteristics of the interview participants included in this study. First, the level of education completed by those in this research was relatively high. In addition, there was a related issue concerning the majors of participants when they attended college. Several of those who completed interviews majored in the discipline of Sociology, Social Work, or Physical/Occupation while attending college, which are all fields that provide an emphasis that students develop an understanding of the social circumstances disabled people face. These two traits of some of the participants are factors that likely impacted the responses provided by participants. Namely, participants may have been influenced by their major areas of study by indicating their heightened awareness of discrimination that would likely be experienced by an impaired child, etc.

Two other related characteristics of some of the participants that likely shaped their reflections about topics related to having an impaired child concerns the occupations and the amount of interaction some have with impaired people. Three participants, for example, reported being in occupations where they, specifically, work with families where there is a child with an impairment. Additionally, a majority of women in my sample have family members who are impaired and many women, also, have worked at jobs where they worked with fellow employees who had impairments. Similar to the concern noted regarding the participants' level of reported educational attainment, these participants are more likely to be aware of ways in which social circumstances impact the lives of those with impairments and to be more knowledgeable about life with an impairment. Future research could address these related issues by including a sample of women that have more diverse characteristics, especially as they relate to educational attainment, occupations, and level of interaction with impaired people.

Directions for Future Research

While the findings from the study provide some significant findings, the results of this research also demonstrate the need for additional analysis of the representation of a potentially impaired child in medical discourse. One specific area of future research is an examination of additional pregnancy guidebooks. Additional pregnancy texts analyzed might include those directed at other audiences, such as those written for expecting fathers or specific racial/ethnic groups. Further assessments of pregnancy guides might also incorporate an historical analysis of the evolution of perspectives, language, and meaning conveyed in pregnancy guides over time, since these books have begun to be published. A final area of research utilizing content analysis of pregnancy guides that might help reveal more about the impact of social and cultural values involves assessing texts from various societies around the world. This research would allow for a cross-cultural understanding of medical perspectives about disability to be realized.

As this research involved only a small sample of women who commented on two short passages from the pregnancy guides under investigation, other research could also incorporate a larger number of participants and could involve participants reading more lengthy passages and additional selections of the texts. Additional studies could also involve participants with particular traits, such as one study that includes the perspective of expecting fathers or partners, women who are currently pregnant with their first child in comparison to those who have already had children in the past, etc. The interpretations of the meaning of the text in pregnancy guides might differ in interesting ways between groups, depending on their positionality in regard to the event of pregnancy.

Beyond studies of pregnancy guides and the discourse about potentially having an impaired child, further research into the topic of modern representations of disabled people, in general, need to continue. Analysis of additional forms of media portrayals of disabled people, involving images and/or language, would assist in painting a more complete picture of current sentiments regarding those with impairments. Portrayals could be compared across many different forms of media, such as in television advertisements or shows, in online media, or across additional print sources, such as medical pamphlets or in popular books.

APPENDICES

APPENDIX A: Keyword List

a bad outcome
a genetic component to the disease
a healthy fetus
a natural selection process
a problem
anxiety
avoid
babies are…healthy
baby's long-term well-being
baby-to-be's well-being
birth defects
birth defects
cause for concern
chance of surviving
chromosomal defect
chromosomal defects
chromosomal problems
chromosomal…genetic defect
complications
condition…is incompatible with normal life
crisis
Cystic Fibrosis
danger
dangerous
defective embryo
deficits- physical and intellectual
detect disorders
don't freak
DON'T PANIC
Down syndrome
excess of…nutrients can be hazardous
fetal abnormalities
fetus was not normal
freaked
genetic counseling
genetic counselor
health warranted suspicion
healthy
healthy babies
healthy baby
healthy pregnancy
heart defects
increased risk
It…had something really wrong with it
keep…the baby healthy
life-threatening disorders
likelihood of having a problem
long-term disability
mental deficits
might be a problem
motor development deficits
neural-tube defects
normal and healthy child
normal pregnancies and healthy babies
not viable
other testable genetic abnormalities
perfectly normal baby
precautions to avoid
prepare for the healthiest…baby
progressing normally
reassurance
reassure
reduce the risk of neural tube defects
risk
risk factors
risk for chromosomal abnormality
risky
risky pregnancy
safe for your baby
safety
sick
Sickle-cell anemia

genetic disease
genetic disorder
genetic health
genetic irregularity
genetic or chromosomal disorders
genetic problems
genetic screening
genetic tests
genetically abnormal
growing up healthy
harmed my baby
harmful to the fetus
have to decide
having to terminate the pregnancy
health complications
health of your baby
slit your wrists
spina bifida
long-term physical/intellectual deficits
Tay-Sachs
terminate the pregnancy
terminating one or more…fetuses
the strongest…can safely…develop
weak with fear and near panic
weeding out the imperfect ones
will my baby be healthy?
work yourself into a lather
worry
worry list
worrying
your health and the baby's

APPENDIX B: Interview Flier

VOLUNTEERS NEEDED FOR INTERVIEWS!

- I am conducting research to learn more about the perceptions people have of those with disabilities for my dissertation research at MSU.

- **ELIGIBILITY CRITERIA:**
  - ✓ Women
  - ✓ 18-50 years of age

- Interviews will take about 30 minutes. There will be a small monetary gift for participating in an interview.

CONTACT: UNDERW89@MSU.EDU OR (269) 967-6027

Kimberly Underwood
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Contact for perceptions of disability study

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APPENDIX C: Consent Form

Perceptions of Disability Research Study Consent Form

You are being asked to take part in a research study. Researchers are required to provide a consent form to inform you about the project, to convey that your participation is completely voluntary, to explain risks and benefits, and empower you to make an informed decision. Please read this form carefully and ask any questions you may have before agreeing to take part in the study.

Researcher and title: Kimberly Underwood, Doctoral candidate

Researcher and title: Raymond Jussaume, Professor

Department and institution: Department of Sociology, Michigan State University

What the study is about: The purpose of this study is to examine how people construct meanings associated with disability given the context of information provided in pregnancy guidebooks. You must be between 18-50 years of age, female, and not currently pregnant in order to take part in this study.

What we will ask you to do: If you agree to be in this study, we will conduct an interview with you. The interview will begin with a few questions about your current understandings about having an impaired child. Next, you will be asked to read a short passage of approximately 2-4 sentences from a pregnancy guidebook. After reading the information, you will be asked a few questions about what meanings you have about the information presented. The interview will take about 30 minutes to complete. With your permission, we would also like to tape-record the interview.

Risks and benefits: I do not anticipate any risks to you participating in this study other than those encountered in day-to-day life. However, if you feel that any of the questions asked are too sensitive or you are not comfortable answering them, please let me know. I encourage you to let me know this at any stage of the interview. There are no benefits to you in completing this interview. However, I appreciate your involvement in this research because it helps me with completing an important study concerning disability that will also aid me in completing my dissertation work.

Compensation: I am offering you $5 in compensation for taking part in this interview. You will receive the $5 for any participation in the interview, not just for completing it.

Privacy and confidentiality: The records of this study will be kept private. In any sort of report we make public we will not include any information that will make it possible to identify you. Research records will be kept in a locked file; only the researchers will have access to the records. If we tape-record the interview, we will destroy the tape after it has been transcribed, which we anticipate will be within approximately 6 months of its taping. No names or other specific identifying information will be stored with the data.

Perceptions of Disability Research Study Consent Form

Taking part is voluntary: Taking part in this study is completely voluntary. You may skip any questions that you do not want to answer. If you decide to take part, you are free to withdraw at any time.

If you have questions: The researchers conducting this study are Kimberly Underwood and Professor Raymond Jussaume. Please ask any questions you have now. If you have questions later, you may contact the researchers at:

Kimberly Underwood at underw89@msu.edu
509 E. Circle Drive Room 316, East Lansing, MI, 48824
(269) 967-6027

Raymond Jussaume at jussaume@msu.edu
509 E. Circle Drive Room 317, East Lansing, MI 48824
(517) 353-6790

If you have any questions or concerns regarding your rights as a subject in this study, to obtain information or offer input, or register a complaint about this study, you may contact the Institutional Review Board (IRB) at Michigan State University's Human Research Protection Program at:

(517) 355-2180
Fax (517) 432-4503
E-mail: irb@msu.edu
Olds Hall, 408 West Circle Drive #207, MSU, East Lansing, MI 48824.

You will be given a copy of this form to keep for your records.

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

☐ Please check this box if you consent to having the interview tape-recorded.

Your Signature ____ Date ______________

Your Name (printed) ____

This consent form will be kept by the researcher for at least three years beyond the end of the study and was approved by the IRB on 5/27/15.

APPENDIX D: Interview Questions

Demographic Questions

1. What is your age?
2. What sex/gender do you identify as?
3. What level of education have you completed?
    a. (How many years of college have you completed?)
4. What is your approximate family income per year?
5. What is your occupation, if you have one?
6. How would you describe your race and ethnicity? (How do you identify?)
7. What is your relationship status?
8. Do you have any children?
    a. If yes, what is the age of your child(ren)?

Initial assessment

1. If you were pregnant (or your partner was pregnant) and the doctor told you that tests have come back indicating you are having a healthy child, how would you react to that?
2. What meaning would having a “healthy child” have for you?
3. What would you think if the test results had, instead, indicated there is a chance or risk of having a child with a disability, such as Down Syndrome?

4. Have you ever read any part of a pregnancy guidebooks, such as *What to Expect When You're Expecting*? ____ No ____ Yes
    - (If yes-) How do you feel that this information helped shape how you feel about having a "healthy" versus an "unhealthy" child?

<u>Reading Passage Questions</u>

PASSAGE #1

1. Do you feel this passage gives a more positive, neutral, or negative emphasis concerning having a child with a disability?
2. Why do you feel this way about the passage?
3. In your opinion, what meaning is expressed about the specific terms they use to describe a disabled person?
4. Is there any other comment you would like to make about what you just read?

PASSAGE #2

a. Do you feel this passage gives a positive, neutral, or negative emphasis concerning having a child with a disability?

b. Why do you feel this way about the passage?

c. In your opinion, what meaning is expressed about the specific terms they use to describe a disabled person?

d. Is there any other comment you would like to make about what you just read?

Passage #1

[When discussing the screenings that take place in the first-trimester:]
"This screening test doesn't directly test for chromosomal problems, nor does it diagnose a specific condition. Rather, the results merely provide you with your baby's statistical likelihood of having a problem. An abnormal result on the combined screening test doesn't mean that your baby has a chromosomal problem, just that he or she has an increased risk of having one. In fact, most women who have an abnormal result on their screening test go on to have a perfectly normal and healthy child. At the same time, a normal result is not a guarantee that your baby is normal, but it does mean that it is very unlikely that your baby has a chromosomal defect" (Murkoff and Mazel 2008:61).

Passage #2
Needed background information: [Amniocentesis, often called amnio, is recommended for women who will be older than 35 on their due-date. It is also recommended for women who have already borne children with birth defects, or when either of the parents has a family history of a birth defect for which a diagnostic test is available. Another reason for the procedure is to confirm indications of Down syndrome and certain other defects which may have shown up previously during routine maternal blood screening.] (The Free Dictionary 2015)

The actual passage: "The reasons we are terrified of amnios are threefold. First, with the long needle they use, we think it will hurt like a son of a gun. Second, our genetics counselors or OBs have legally been obligated to tell us that there is a small chance of the test itself harming the fetus or causing the miscarriage of a healthy fetus. And third, and most agonizing of all, if the amnio tells us, God forbid, that our baby is genetically abnormal, we would have to decide whether to terminate the pregnancy" (Iovine 2007:91).

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