

Disabling the Rhetoric of Prenatal Genetic Testing:
A Critical Analysis of Online Pregnancy Self-Help Literature

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Abstract

Drawing on literature about the disability rights critique of prenatal genetic testing, this article consists of a critical analysis of a type of text in which socially-constructed negative attitudes about disability may be present: online pregnancy self-help literature about prenatal testing. The critique incorporates scholarship on the intersection of genetics and rhetoric in order to clarify rhetorical strategies used by writers of these online articles. The analysis shows that disability is rhetorically constructed as part of a tragedy narrative through negatively-connoted word choices and reductionist descriptions in the writing. Furthermore, the benefits of testing are construed as the ability of parents to treat or emotionally prepare for their child's condition, as well as consider abortion, though the success of treatment and the possibility of abortion are masked or glossed over, giving parents an inaccurate picture of prenatal testing's purpose and benefits.

Keywords: pregnancy, genetics, prenatal testing, rhetorical analysis, disability rights critique

L'invalidation de la rhétorique de dépistage génétique prénatal :

Une analyse critique de la documentation d'auto-assistance sur la grossesse en ligne. Cet article présente une analyse critique, se fondant sur la littérature analytique issue du mouvement des droits des personnes handicapées, d'un genre de texte dans lequel les attitudes négatives sur le handicap sont exprimées et socialement construites, soit, la documentation d'auto-assistance sur le dépistage prénatal. Cette critique inclue des études scientifiques et académiques se retrouvant à l'intersection de la génétique et de la rhétorique, afin de clarifier les stratégies rhétoriques qui sont utilisées par les auteurs de ces articles en ligne. L'analyse montrera que le handicap est construit rhétoriquement dans ces textes, à travers un récit

tragique, et par le choix de mots à connotations négatives, et des descriptions réductives. En outre, les avantages du dépistage génétique sont interprétés comme étant la capacité des parents à traiter, ou à se préparer émotionnellement, pour l'état de leur enfant, ainsi que la considération d'avortement. Et, ce, même si le succès d'un traitement thérapeutique et la possibilité de l'avortement sont masqués, ou passé sous silence, donnant aux parents une image inexacte du but et des avantages du dépistage prénatal.

Mots-clés: grossesse, génétique, diagnostic prénatal, analyse rhétorique, critique des droits des personnes handicapées

Disabling the Rhetoric of Prenatal Genetic Testing:
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A September 2011 article in *Discover* magazine introduces readers to what it calls a “miracle”: the ability of researchers to sequence a fetus’ genome at 9 weeks, allowing doctors to diagnose genetic disease and possibly features of the child’s appearance from just a small sample of the mother’s blood. Some researchers predict this technology may be available for widespread use by 2017. “That’s not much time,” write the authors, “for prospective parents, genetic counselors, and legislators to consider how to handle the flood of fetal genetic information that science is about to unleash” (Barth, 2011). Such scientific advances, and the ways these advances are promoted to the public, also serve as an opportunity for scholars in disability studies to examine how seemingly objective language in medico-scientific discourse can mask troubling assumptions about prenatal genetic diagnosis. This article responds to the exigence created by this changing technology, and the associated ethical concerns, by critically analyzing a type of text in which socially-constructed negative attitudes about disability may be present: online pregnancy self-help literature about prenatal genetic testing.

Prenatal genetic testing, originally offered to pregnant women considered high risk but now frequently offered to all pregnant women (Tremain, 2006, p. 44), consists of both screening tests (such as a multiple-marker screening or maternal serum screening) which assess a mother’s *risk* for carrying a baby with a genetic disorder, as well as diagnostic tests (such as amniocentesis and chorionic villus sampling), which determine whether a baby does have a certain genetic disorder (“Prenatal Tests,” n.d.).

While many praise the ability of these technologies to inform women’s and couples’ decision-making processes, many others, among them bioethicists and activist groups, have

objected to these practices for various reasons. For example, disability rights activists' arguments, upon which my critique is largely based, concern the messages that the practice of prenatal genetic testing and selective abortion send about the value of people with disabilities. Moreover, feminists have questioned whether knowledge gained from genetic tests is truly empowering for women, and to what extent women's consent is truly informed.

According to Lippman (1991), "Western biomedicine does not just describe a pre-existing biological reality, but is grounded in particular social and cultural assumptions" (p. 16). Therefore, it is valuable to examine the biomedical information aimed at the public, specifically pregnant women, regarding pregnancy, prenatal genetic testing, and disability. To that end, this article engages in a close, critical analysis of the language in online pregnancy literature to show examples of how disability is rhetorically constructed in a negative way. Specifically, this analysis finds that the online articles construct disability as part of a tragedy narrative by using negatively-connoted word choices and reductionist descriptions. The possibility of carrying a child with a disability is described in terms of "risk," while in comparison, risks of actually undergoing the testing are minimized if at all mentioned. Furthermore, the benefits of testing are construed as reassurance or the ability of parents to treat or emotionally prepare for their child's condition, as well as consider abortion, though the success of treatment and the possibility of abortion are masked or glossed over, giving women and couples an inaccurate picture of prenatal testing's purpose and benefits. This is problematic because pregnant women may gain their initial impression of certain disabilities, of the possibility of carrying a child with a disability, and of the purpose of genetic testing based on this information, which, despite its veneer of scientific objectivity, is a reflection of society's limited perspectives on disability.

Background and Literature Review

Prenatal genetic tests have been developed not only (and not primarily) to screen for fatal or life-threatening conditions, but also for conditions that can result in a range of disability, such as Down Syndrome, spina bifida, and cystic fibrosis. Some scholars question medicine's practice of reducing these widely variable conditions to a single label, such as "mental retardation" to describe Down Syndrome (Rapp, 1988, p. 150). Parens and Asch (1999), authors of a supplement to the Disability Rights Critique of Prenatal Genetic Testing (a report by the Hastings Center, a bioethics research institution), also argue that the act of prenatal diagnosis and selective termination of pregnancy makes a part (the disability) stand in for the whole person, and developers and marketers of these tests socially construct the view that some disabilities are worse than others by developing tests for some disabilities and not others (p. 2). A history of discrimination against people with disabilities (including infanticide and sterilization) has set the stage for continued unexamined stereotypes and biases, some which appear in even recent bioethics and medical literature (p. 8).

To study such stereotypes, Stowe et al. (2007) conducted interviews and focus groups with people with disabilities and in the disability rights movement and found that they had similar concerns about the messages sent by prenatal testing. Specifically, the interviewees were concerned that the practice sustains ignorant stereotypes of suffering, and the belief that disability places an economic burden on society and is the predominant aspect of one's identity. Interview subjects also recognized the dangers of "overconfidence in scientific objectivity, reporting results that overreach the methods used, and pushing scientific answers for value-based questions" (p. 204). The authors of the study argue that while literature today may not be as overt

as the eugenics propaganda of the past, its underlying assumptions still fail to counteract stigma and discrimination (p. 204).

Prenatal genetic testing arose in the cultural context of what Lippman (1991) labels geneticization: “an ongoing process by which individuals are reduced to their DNA codes [and] the process by which interventions employing genetic technologies are adopted to manage problems of health” (p. 19). She considers prenatal genetic diagnosis to be the most routine and prevalent application of the technologies of geneticization (p. 19). Jennings (2000) would add that another cultural context that makes the acceptance of prenatal genetic testing possible is the medicalization of pregnancy, which “surrounds pregnancy with the discourse of disease, danger, risk, and defensive measures against misfortune” (p. 136), making this testing appear to be the “responsible” course of action for a pregnant woman. As Condit (2000) says, because the genetic model views bodies as flawed from conception, treatment comes in the form of prenatal selection, placing more responsibility for the health of children on women and the choices they make in response to genetic test results (p. 125). She adds that genetics professionals claim that over time, therapies will be developed to treat pre-existing disorders, though there is no clear timeframe for these developments (p. 132).

Because of the dearth of actual genetic therapies that can be administered prenatally, the basic function of prenatal diagnosis, according to Asch (2002), is to allow women the choice to abort or carry to term, although this basic function is rarely openly acknowledged. Shildrick (2004), too, notes that despite the testing’s purported function as just a routine component of responsible pregnancy management, it is in fact offered on the assumption that women will abort those fetuses considered to be defective (p. 154).

Due to the controversy and complex technical concepts embedded in this practice, the profession of genetic counseling arose to help patients understand the information provided by the tests and their options. This profession has a commitment to non-directiveness, but as Asch notes, many genetic counselors do not practice in a way that shows support for all choices, especially the choice not to abort an affected fetus (p. 334). Besides Asch, several other feminist scholars have commented on the lack of women's true choice when it comes to responding to prenatal genetic tests (Katz Rothman, 1993; Karpin & Savell, 2012; Rapp, 1999; Shildrick, 2004; Tremain, 2006). For example, Katz Rothman (1993), author of *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*, argues that amniocentesis and selective abortion only provide the illusion of free choice because societal expectations (such as a preference for "perfect" children) structure the choices that are seen as more and less legitimate (p. 14). Likewise, Karpin and Savell (2012), in their analysis of a prenatal genetic testing decision-making aid, explain that choosing to be uninformed by not having testing can be seen as not only abnormal, but irresponsible (p. 49-50).

Geneticization and the view of prenatal care as risk management have become so embedded in culture that it is easy to overlook the values about disability hidden in these discourses, from the language used in genetic counseling appointments and scholarly medical literature, to the less-technical information aimed at pregnant women facing decisions about whether to undergo genetic testing and how to respond to genetic testing results. Rhetoricians Lindblom and Dunn (2003) state that one of the contributions of disability studies to rhetoric studies has been in revealing how categories like "disabled" or "normal" are not necessarily inherent medical conditions but are, to a large extent, socially constructed. They call rhetoric scholars to move from just a recognition of the constructed nature of disability to "action that

informs meaningful, public reconstructions of what counts as ‘normal,’” (p. 169), and one place to start is in critiquing publicly available information such as prenatal genetic testing articles on the internet.

Methods

Artifacts

My artifacts for analysis consist of a set of online articles from U.S. websites, on the topic of prenatal genetic testing and targeting pregnant women. I have chosen articles with an audience of pregnant women because the primary responsibility for the health of the family members is typically placed on the woman (Lippman, 2001, p. 27). Indeed, this responsibility may manifest in “tak[ing] pregnancy as a reading assignment” (as cited in Georges & Mitchell, 2000, p. 184). And, as Karpin & Schavell (2012) acknowledge, while there are myriad other factors affecting parents’ decisions regarding prenatal testing (among them negative stereotypes, future plans, personal experience, and resources), pregnancy literature is certainly one factor that plays into the process (p. 58). Online pregnancy self-help literature, in particular, could be assumed to be growing in popularity as more people are able to access the internet and as personal involvement and self-education in healthcare become more valued and widespread.

My goal with this analysis is not to provide quantitative data, but rather to provide a qualitative description of patterns and themes in the texts. Therefore, my methods for selecting articles are more naturalistic than systematic: I tried to replicate the approach that a pregnant woman might take to seek initial information about this topic. I limited my artifacts to sites that appeared near the top of search engine results for searches such as “pregnancy,” “prenatal tests,” and “amniocentesis,” assuming that those represent the most popular or at least the most accessible web pages. I then limited the articles in my survey to six about prenatal testing and

genetic counseling (see list below), since these topics are likely to touch on some of the most controversial and sensitive issues surrounding such tests:

- A. All About Prenatal Testing During Pregnancy. (n.d.). Retrieved July 17, 2012, from <http://www.whattoexpect.com/pregnancy/pregnancy-health/prenatal-testing.aspx>
- B. From ultrasounds to amniocentesis, your guide to prenatal genetic screening. (n.d.). Retrieved July 17, 2012, from <http://www.justthefactsbaby.com/pregnancy/article/is-prenatal-genetic-testing-right-for-you/122>
- C. Prenatal genetic counseling. (n.d.-a). Retrieved July 17, 2012, from http://www.babycenter.com/0_prenatal-genetic-counseling_1607.bc
- D. Amniocentesis: American Pregnancy Association. (n.d.). Retrieved July 17, 2012, from <http://www.americanpregnancy.org/prenataltesting/amniocentesis.html/>
- E. Amniocentesis: BabyCenter. (n.d.). Retrieved July 17, 2012, from http://www.babycenter.com/0_amniocentesis_327.bc
- F. Prenatal Tests. (n.d.). Retrieved July 17, 2012, from http://kidshealth.org/parent/system/medical/prenatal_tests.html

The articles range in tone from more scientific and formal (e.g., *Just the Facts*) to more casual and personable (e.g., *What to Expect*), but they all address similar topics, such as the purpose of genetic testing, statistics on odds of giving birth to a baby with birth defects, the testing procedure, and responding to a positive test result (the word “positive” in this context indicating that a defect or risk for a defect has been detected).

Because this is a limited set of artifacts, conclusions cannot be extrapolated to all literature about prenatal genetic testing aimed at pregnant women, which is not the goal of this article. Instead, my goal is to engage in a close rhetorical analysis of the language in this data set

in order to illustrate prominent themes and provide key examples of how disability is rhetorically constructed in the context of pregnancy and genetic testing. In this sense, the objective of my study aligns with that of Karpin and Savell's (2012) close analysis of the wording in two pieces of health literature on prenatal testing, in which they illustrated how such literature contains assumptions that can influence women's decisions.

A further limitation to consider is that this type of text is just one of many sources of information that pregnant women may consult throughout their pregnancies, and some women do not seek information from this source at all (for example, those without internet access), which limits the conclusions I can make about the influence of the articles.

Research Questions and Analytical Methods

Lippman (1991) urges readers to “continue to listen to the stories being told about prenatal testing and screening with a critical ear, situate them in time and place, question their assumptions, demystify their language and metaphors and determine whether, and to what extent, they can empower women” (and, I would add, people with disabilities) (p. 49). This analysis is a response to that call – an opportunity to examine the stories in these online articles, contextualize them, and break down the language use.

My goal was to begin the analysis with an idea of the most prevalent rhetorical strategies that the articles' authors may be using, based on other scholarship on genetics writing or discourse. For example, I used Rapp's (1999) and Lippman's (1994) discussions of the rhetoric of reassurance and control in genetics discourse, Shakespeare's (1998) work on narratives of tragedy and optimism in popular media accounts of genetic technology, and Scott's (2003) rhetorical-cultural analysis of the knowledge enthymeme in HIV testing arguments. Drawing on

others' work gives me a bounded starting point and serves as the basis for specific research questions to ask of the texts, such as:

- 1) How is the purpose of the test defined, and how does the purpose differ depending on whether there is a positive or negative test result?
- 2) What narratives of tragedy or optimism are used to promote prenatal testing?
- 3) How is disability rhetorically constructed in the articles, based on word choice and descriptions of disabilities?

I read and coded each online article, taking notes on answers to these questions. I excluded any portions of the articles about non-genetic prenatal tests (such as ultrasound or maternal blood tests not intended for fetal diagnosis). Based on my findings, I developed subcategories for the answers, around which the results section will be organized. In the interest of concision, I will refer to the articles by the lettered labels I gave them in the "Artifacts" section.

As will be evident in my critique of these articles, I come to this analysis sharing many of the values embodied in the disability rights critique of prenatal genetic testing. However, my purpose with the analysis is not to condemn prenatal genetic testing per se, but to bring to light rhetorical strategies and patterns that should be challenged due to the roles they may play both in perpetuating negative stereotypes about disability and in directing parents' decision making.

Results and Discussion

1. How is the purpose of the test defined, and how does the purpose differ depending on whether there is a positive or negative test result?

In every case, the purpose of the testing itself is construed as obtaining information, reflecting an underlying value of knowledge. For example, articles state that prenatal testing can "help you find out if your baby is at risk [for certain genetic defects]," (B, para. 1) "detect

potential fetal abnormalities,” (B, para. 2), or “tell you for sure whether your baby has certain genetic problems” (C, para. 11). In these cases, the purpose is defined as gathering specific information about defects or problems. In other cases, though, the purpose is construed more vaguely as gaining information about the baby’s health; for example, prenatal testing allows women “to get the most accurate view possible of your health and that of your baby-to-be (and catch any pregnancy complications early on)” (A, para. 3), or allows your healthcare practitioner “to gather information about your baby’s health” (E, para. 1).

In these latter statements, the specific kind of health information to be gathered (about genetic defects) is obscured, making prenatal testing appear to be a normative aspect of prenatal care that any woman would pursue if she cares about her baby’s health. Press (2000) noticed a similar phenomenon in interviews with women receiving MSAFP or multiple-marker screening, offered to women with no apparent risk of birth defects. Since it detects an anomaly that is not treatable, its true intent is to allow the option of aborting an affected fetus. However, women described the screenings as “responsible maternal actions that provided useful information,” “were reassuring,” and were meant to help “protect the fetus” (p. 219).

Reassurance and knowledge. It is unsurprising that gaining information is considered the primary purpose of testing; however, the rhetoric becomes more revealing when the writers outline the purpose of that information, because that information can come in the form of a positive or negative test result. According to the articles, one purpose or benefit of information (assuming the test comes back negative, indicating no problems) is that it provides reassurance or peace of mind for women. For example, “the vast majority of these tests will confirm that everything is just fine” (A, para. 3), “if everything’s okay, your mind will be put at ease” (E, para. 23), and testing “can help to reassure [women] and keep them informed throughout their

pregnancies” (F, para. 2). As Lippman (1991) argues, “The language of control, choice and reassurance certainly makes prenatal diagnosis appear attractive” (p. 23). Despite the potential benefit of reassurance, according to Katz Rothman (1993), this benefit must be weighed against of the anxiety that amniocentesis can create by defining and drawing attention to the “problem” of disability.

Not all of the articles emphasized reassurance as a benefit. Instead, most of the articles give more weight to technical descriptions of the information that testing can determine, but gloss over what women are to do with that information (or what the information is to do for women): one article, after describing the technical aspects of amniocentesis and chorionic villus sampling, vaguely states that “the issues are complex, but genetic counseling is available in most areas to help you decide what is right for you” (A, Chorionic Villus Sampling, para. 2). This points to an implicit assumption in the articles that knowledge in and of itself is reason enough to test, a variation on the “knowledge is power” commonplace, in which the “knowledge enthymeme” finds its basis. Scott (2003) defines the knowledge enthymeme as “a disciplinary body of persuasion that exaggerates the power and beneficial effects of testing and the knowledge it produces” (p. 44), an argumentative strategy that certainly has parallels in the discourse of prenatal genetic testing.

Treatment. As established in the literature review, since very few in-utero therapies exist for the conditions detectable by prenatal genetic testing, it is interesting how testing is described as beneficial for those who receive positive test results. One purpose or benefit of information (in the case of a positive test result) is to allow for treatment or to “pursue potential interventions” (D, para. 14). Other articles mention that “some” (F, para. 3) or “a few” (E, para. 19) conditions are treatable. Another article, when addressing prenatal testing generally, says that in the case

that things are not “fine,” they “can be made so with simple, standard, follow-up care” (A, para. 3). It states that “the vast majority of tests” will lead to this outcome, thereby ignoring the cases in which things are not “fine” and cannot be made so. Presumably, then, women do not need to worry about that circumstance until they are faced with it. All but one of the articles in my survey make some mention of treatment as an option.

However, the articles never give statistics about the percentage of disorders that can be treated in the womb, the types of disorders that can be treated, what form the treatment may take, or how successful treatment typically is. In contrast, the articles do not shy away from listing the statistical odds of fetal birth defects and the factors that affect risk. This unbalanced presentation of information leaves women with a sense of the probability of having a baby with birth defects, but no realistic sense of the probability of treatment. The closest one article gets to the uncomfortable truth is acknowledging that “more abnormalities can be diagnosed in a fetus than can be treated or cured” (F, para. 6). This unbalanced information is problematic because, according to Shakespeare (1998), “the narratives of cure and hope which abound in the literature, especially in the media reception of discoveries, conceal very limited options for those in receipt of the new genetic knowledge” (p. 677).

Preparation. A more-emphasized benefit of information in the case of a positive result is emotional and practical preparation. For example, prenatal testing gives couples “time to plan and get prepared,” which may take the form of “optimizing where the baby will be born and the care at the time of delivery” (B, para. 11). Emotionally, women have time to “grieve for the perfectly healthy child [they] had hoped for and deal with any guilt [they] may feel” (C, para. 21). Being informed and able to prepare in advance is construed as more beneficial than ignorance, since not testing in the first place is rarely mentioned as an option.

Abortion. The proverbial elephant in the room is that knowledge of genetic defects may lead to a decision to abort. Although prenatal genetic testing was developed to enable the diagnosis and abortion of fetuses deemed defective (Rapp, 1999, p. 70), this purpose is largely obscured in the artifacts, if mentioned at all. One way in which this is obscured is in the word choice of “termination” or “end the pregnancy” in lieu of the more emotionally and politically charged term “abortion” (A, B, E). The only article that uses the word “abortion” at all is in one about genetic counseling, under the heading, “I’m completely opposed to abortion. Should I still meet with a genetic counselor?” (C). The answer provided is that couples should consider prenatal genetic testing anyway, because “the information offered provides reassurance in the face of uncertainty and some sense of control over the situation.” In other words, opposition to abortion in and of itself is not a good enough to reject genetic testing. In another article, the assumption of abortion as the purpose of prenatal genetic testing is rejected in a quotation from a doctor: “The biggest misconception is that having a screening or diagnostic test means that you want to have a termination” (B, para. 11). While it may be true that some women will choose testing even if they do not plan to abort, this statement obscures the fact that abortion is a common consequence of a positive test result. In fact, according to Shildrick (2004), in some places such as the UK, most physicians will not authorize testing unless a woman agrees in advance to abort in case of a positive result (p. 154).

Another way in which abortion is obscured is its placement in the articles. In all but one case, the insinuation of abortion is reserved for the very end of the article, after the incidence and risk for prenatal defects is outlined, or is the last in a list of reasons to test (D). Also, reasons why a woman may choose to abort are never discussed – that discussion is deferred to genetic counselors.

Abortion is also obscured by being subsumed under the vague category of “making decisions,” usually with the assistance of a genetic counselor. For example, a genetic counselor can “help you decide what is right for you” (A, Chorionic Villus Sampling, para. 2), “help you decide on the best course of action for you and your family” (B, para. 11), “guide you through... other options available” (C, para. 1), or “help you...discuss your options” (F, para. 98), and a positive diagnosis gives you an opportunity to “make a decision about carrying the child to term” (D, para. 14). This strategy of frequently referencing “decisions” and “options” is rhetorically effective, because it appeals to the highly-vaunted value of choice. Also, the use of the words “right” and “best” imply that the decision will ultimately be a good one. Press’ (2000) study of MSAFP screening can again be likened to prenatal genetic testing: by treating the screening as just another aspect of routine prenatal care, the real purpose (to allow abortion of affected fetuses) was obscured (p. 219).

2. *What narratives of tragedy or optimism are used to promote prenatal testing?*

Shakespeare (1998) identifies a narrative of genetic intervention, in which genetic interventions contribute to human health and allow the avoidance of suffering, and narratives of optimism and tragedy are two dimensions of this grander narrative (p. 669). I examined whether these two narratives appear in this literature.

Optimism. According to Shakespeare, the optimism narrative can be characterized by words such as “cure” and “treatment,” which I began to explore above. To further trace the narrative of optimism, I looked for the ways in which prenatal genetic testing is praised. As mentioned earlier, prenatal testing is considered valuable because of its ability provide information, and that information is framed as largely beneficial and accurate. Article A provides

the most obvious example of optimism, saying that “most of this stuff [prenatal testing] is routine, pretty painless – and absolutely beneficial” (para. 2) and can be thought of as “your first step in nurturing your child” (para. 3). While there are many prenatal tests that are noninvasive and do lead to treatment, this statement ignores the fact that other tests, such as amniocentesis and chorionic villus sampling, carry a risk of miscarriage and that, were a result to come back positive, there are few opportunities to “nurture” that child through treatment after diagnosis.

Another way in which prenatal testing is framed optimistically is by downplaying the limitations of the testing. Articles state that testing allows you to “get the most accurate view possible of your health and that of your baby-to-be” (A, para. 3), that amniocentesis has a “high” accuracy rate of 98-99% (D, para. 9), “is more than 99 percent accurate” (E, para. 5), and “can tell you for sure whether your baby has certain genetic problems” (C, para. 11). Article F is the most clear about the limitations of the accuracy of the tests, saying that “because many aren’t definitive, even a negative result may not completely relieve any anxiety you may be experiencing” and some women may forego some testing “because many women who have abnormal tests end up having healthy babies” (para. 97). Although this takes a less optimistic tone regarding what information prenatal tests can realistically provide, it suggests that the major problem with prenatal testing is its lack of complete accuracy, thereby implying that it *would* be a good way to reassure women if it could be made more accurate.

Finally, optimism emerges in the framing of the risks of the procedure. Article D claims that amniocentesis is considered a “safe” procedure, despite its risks. Article A minimizes risk by saying, “Amniocentesis increases your chance of miscarriage by one percent, but it’s even less in major cities” and most physical side effects for the mother “usually go away on their own within a day or two” (Amniocentesis, para. 7). The article’s description of the risks of CVS is bleaker,

suggesting that a woman may want to have the procedure done at a specialized medical center to lessen the risk of miscarriage, and that she is “likely to be pretty tired and emotionally drained” (Chorionic Villus Sampling, para. 6). At least one article is more up front about risks, giving numbers about the risk of miscarriage without any commentary (B), but the majority of the articles, while supposedly helpful by putting risks in perspective for women, make assumptions about what a woman should consider to be “safe,” “risky,” or “accurate.”

The optimism thread is present throughout the articles in that women are rarely discouraged from testing, the implication being that this testing is beneficial enough that most women (or at the very least, those with risk factors) should want it. Also, very rarely are any emotional or psychological risks of testing discussed, besides the mention that “some prenatal tests can be stressful” (F, para. 97) or that women may feel “emotionally drained” afterwards (A, Chorionic Villus Sampling, para. 6). Scott’s (2003) analysis of HIV testing rhetorics is applicable here as well. He says that pro-testing rhetorics both exaggerate the benefits and downplay its contingencies and risks (p. 10). Discourses of prenatal genetic testing, as in HIV testing, fail to adequately address the limitations and drawbacks.

Tragedy. According to Shakespeare (1998), in order to “sell” prenatal genetic testing, the medical industry must frame disability as a problem to be avoided, and genetic testing and selective abortion as the means of avoiding this problem. The articles imply that positive test results are “bad news” (E, para. 17) or “unsettling” (A, Chorionic Villus Sampling, para. 2). Article C says that even if abortion is not an option, knowledge of a defect in advance can allow couples to “grieve for the perfectly healthy child you hoped for” (para. 21), suggesting that a positive test result is an occasion for grief. This is not to say that positive test results cannot legitimately be considered “bad” by women and couples, but considering the news “bad” *a priori*

leaves little room for alternative, more positive interpretations of such results. Additionally, there are no reasons offered for *why* a given test result should be considered bad, thus leaving assumptions about disability unquestioned.

Article C is the only one that begins to address the potentially complex decision-making process faced by women and couples who learn of a positive test result. It gives only one example of a factor to be considered, one which appeals to a woman's sense of familial responsibility: the impact of a "handicapped child" on the woman's family. The two example questions that the article poses are "Would they [your other children] feel resentful of their sibling's lifelong needs for special care? Or might the experience enhance the older kids' life by teaching empathy and tolerance?" (para. 18). Besides posing a false dichotomy of responses that children may have to a disabled sibling, these questions contain hidden stereotypes about the so-called burden of disability and the role of disabled people as teachers or character-builders for others.

3. *How is disability rhetorically constructed in the articles, based on word choice and descriptions of disabilities?*

Word choice. The discussion of the tragedy narrative leads to further examination of ways that disability is rhetorically constructed, such as through word choice. Shakespeare (1998) lists the words "risk," "burden," "severe handicap," "suffering," "abnormality," and "disorders" as among those that contribute to the narrative, and according to Seavilleklein (2009), disability rights activists have objected to such terms because they imply a deviation from the norm and have negative connotations, and she is concerned that these terms may have the power to influence women's decisions. My survey showed that the words "defect," "abnormality," and

“disorder” are used in every article. Other terms used to describe outcomes of positive test results are “disease,” “problem,” “developmental delay,” “retardation,” and “condition,” with the terms “condition” or perhaps “delay” being the only ones without built-in negative connotations.¹ My survey also showed that the term “risk” is included in each article. The term “risk” implies danger and is considered something to be avoided or managed. In Karpin and Savell’s (2012) discussion of risk in the context of prenatal genetic testing, they state that “An ‘at-risk’ status is likely to be understood as an existing danger and may promote fear and anxiety rather than informed decision making” (p. 82). Not only does the use of the term risk, then, create negative associations with disability, but it also limits women’s decision-making regarding testing.

Description of disabilities. As Parens and Asch (2000) warn us, one destructive message sent by prenatal testing is that a disabled person can be reduced to “a single, perceived-to-be-undesirable trait” (p. 2). Asch (2002) adds that “rehabilitation literature is full of examples of how able bodied people think of disabled people not as having specific disabilities, but as being generally incompetent” (p. 329). In light of this, it is important to examine how disability is described in the artifacts, whether in reductionist terms or in broader, more inclusive terms. Ultimately, they tend to describe disabilities reductively. The only article that attempts to define Down Syndrome as anything more than a “chromosomal abnormality” says that it “causes mental retardation and physical defects” (F, para. 18). The same limited approach is taken for spina bifida, which is predominantly described as a “defect,” Tay-Sachs as a “genetic disease,” and cystic fibrosis as a “disorder.”

¹ I recognize the challenge in finding an alternative to this medically-accepted yet negatively-connoted terminology, especially since it is not wise to ignore or downplay the material, physical reality of some of these conditions. Indeed, it is difficult to write this paper about prenatal testing without resorting to these conventional terms. At the very least, I hope this critique can identify the need to pay greater attention to the messages these labels send about people with disabilities, to be aware of the ways that these terms may subtly direct women’s choices, and to consider alternative word choices where possible.

Unfortunately, these labels say nothing about the range of disability or what it is like to raise a child with a given condition. It could be argued that more comprehensive descriptions of these conditions would go beyond the scope of these overview-type articles, and that the articles refer women to genetic counselors for more information. However, reducing these disabilities to single labels is not an ideologically neutral act, and telling readers repeatedly that their baby could be “at risk” for a given condition sends the message that it is inherently negative.

Conclusion

In the previous analysis, I have shown how the articles consider reassurance or knowledge in and of itself to be a valid reason to undergo testing, assuming no problems are detected. In the case that problems are detected, the benefits of testing are construed as the ability to treat or emotionally prepare for the condition, as well as consider abortion, though the success of treatment and the possibility of abortion are masked or glossed over, giving women an inaccurate picture of prenatal testing’s purpose and benefits. I also discussed how the texts emphasize the “high” accuracy and the “low” risk, though that risk is largely considered to be physical (miscarriage), while emotional and psychological drawbacks are minimized if at all mentioned. I argued that disability is rhetorically constructed as part of a tragedy narrative through negatively-connoted word choices and reductionist descriptions.

So why does this all matter? It could be argued that, due to the constraints posed by the genre (length, level of technical detail, etc.), it is unreasonable to expect the authors to address such wide-ranging topics as the probability of treatments for certain conditions or what it is like to live with a child with a given disability. Furthermore, one might argue that the articles do not purport to be the final authority on prenatal genetic testing or factors that a woman should

consider, and instead encourage women to talk with their doctors or genetic counselors. I argue that the assumptions implicit in these articles are still problematic, for several reasons.

First of all, first impressions count. The popularity and prevalence of pregnancy sites suggests that many women wish to take an active and informed role in their healthcare and the health of their baby. Such websites define the normative pregnancy experience and set a standard for what a woman should expect throughout her prenatal care (i.e., the website title *What to Expect*). A woman seeking to be well-educated about her pregnancy will likely encounter material on prenatal genetic testing, whether by seeking it out or in the process of browsing a pregnancy site, and may do so before she hears about it from a doctor or more authoritative source. This could skew a reader's initial impression of prenatal testing towards it being a common practice which carries few risks and many benefits.

Second, some of the articles have a veneer of objectivity and trustworthiness. For example, the very title of one website (*Just the Facts*) suggests that readers will be getting objective, value-neutral information, and many articles use statistics and bulleted lists in a seemingly objective fashion (e.g., "a 30-year-old pregnant woman has a 1 in 1,000 chance of carrying a baby with Down syndrome" (C, para. 2)). This is not to say that presenting data is inaccurate or inherently misleading, but readers may assume that they are receiving *enough* information or unbiased information. According to Lippman (1994), scientists (and, I would add, science journalists) mold raw information into a message, and in so doing, flatten complexity and reflect personal and societal perspectives (p. 12). This is particularly troubling in an era where medicine "is becoming the new repository of truth, the place where absolute and final judgments are made by supposedly morally neutral and objective experts," in the words of disability activist Irving Zola (as cited in Saxton, 2000, p. 148).

Some of the articles make claims of objectivity and goodwill on behalf of medical authorities and genetic counselors. Article C describes genetic counseling in a decidedly positive manner, listing a counselor's role as to "guide you" and "help you" in articulating and sorting out your feelings, making informed choices, and deciding what is "best" for you and your family. Most disturbingly, the article claims without qualification that genetic counselors will not suggest that a woman choose a particular path. As discussed in the literature review, despite a commitment to non-directiveness, the profession is hardly neutral because the technology itself is not.

Moreover, many of the same problematic omissions in the artifacts have also been noted in the interactions between patients and their genetic counselors or obstetricians. According to Powell (2000), one study showed that in conversations about prenatal genetic testing between patients and their healthcare practitioners, the topic of abortion and description of disorders did not occur in most visits (p. 48). It is taken for granted that counselors and doctors will help women make the "right" decision, while greater cultural, economic, and legal factors are overlooked. To some extent, such overly positive and limited rhetoric about prenatal genetic testing shapes parents' expectations and questions they will ask of their doctors.

Positively, all of the articles name conditions under which a woman might be more inclined to seek testing (advanced maternal age being the most common), so none of the articles claim that prenatal testing should be mandatory or universal. It is good that the articles still acknowledge testing as an *option* and not a *requirement*. However, through prioritizing knowledge, reassurance, risk-avoidance, and even responsibility, it becomes difficult for a woman reject this testing, especially if she is labeled as high risk for certain conditions. Women

will face even greater difficulty rejecting testing as it follows the trend of becoming increasingly routinized.

Returning to the “knowledge is power” commonplace invoked in all of the articles, this statement may be true, but for whom, and what kind of knowledge? I argue that women must first be empowered with more knowledge *about* prenatal testing, its purposes, its drawbacks, and the disabilities it diagnoses, before they can be empowered with knowledge *from* the testing. Parents, genetic counselors, medical professionals, and medical journalists must also critically consider the ways in which people with disabilities are disempowered by the reductionist thinking sustained by the practice of prenatal genetic testing and the rhetoric used to describe it.

As Jennings (2000) puts it, “more information is not always better than less if the increase has the effect of narrowing our range of moral vision and attention to the point where some of the broader goals and interests of others or of the community as a whole are lost sight of” (p. 137). When prenatal genetic testing is construed as a natural and logical choice, it forecloses opportunities to problematize the practice, to contemplate the assumptions inherent in it, and to consider what choices we may in fact be *losing* as testing offers us expanding choices, potentially sending women down a path in which they face decisions they never wanted to make. As Katz Rothman (1993) writes, “In gaining the choice to control the quality of our children, we may rapidly lose the choice not to control the quality, the choice to accept them as they are” (p. 11).

References

- Asch, A. (2002). Disability equality and prenatal testing: Contradictory or compatible? *Florida State University Law Review* 30(2), 315–342.
- Barth, A. (2011, September 21). We can now safely sequence a fetus' genome. Is the world ready? *Discover*. Retrieved from <http://discovermagazine.com/2011/sep/16-big-idea-safely-sequence-fetus-genome-world-ready#.UhuqdLx7QiI>
- Condit, C. M. (2000). Women's reproductive choices and the genetic model of medicine. In M. Lay, L. Gurak, C. Gravon, & C. Myntti (Eds.) *Body talk: Rhetoric, technology, reproduction*, (pp. 125–141). Madison, WI: University of Wisconsin Press.
- Georges, E., & Mitchell, L. M. (2000). Baby talk: the rhetorical production of maternal and fetal selves. In M. Lay, L. Gurak, C. Gravon, & C. Myntti (Eds.), *Body talk: Rhetoric, technology, reproduction* (pp. 184–203). Madison, WI: University of Wisconsin Press.
- Jennings, B. (2011). Technology and the genetic imaginary: prenatal testing and the construction of disability. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 124–146). Washington, D.C.: Georgetown U.P.
- Karpin, I. and Savell, K. (2012). *Perfecting pregnancy: Law, disability, and the future of reproduction*. New York, NY: Cambridge U.P.
- Katz Rothman, B. (1993). *The tentative pregnancy: How amniocentesis changes the experience of motherhood*. New York: Norton.
- Lindblom, K., & Dunn, P. A. (2003). The roles of rhetoric in constructions and reconstructions of disability. *Rhetoric Review*, 22(2), 167–174.
- Lippman, A. (1991). Prenatal genetic testing and screening: constructing needs and reinforcing inequities. *American Journal of Law & Medicine*, 17(1–2), 15–50.

- Lippman, A. (1994). The genetic construction of prenatal testing. *Women and prenatal testing*, 13–14.
- Parens, E., & Asch, A. (1999). Special supplement: The disability rights critique of prenatal genetic testing reflections and recommendations. *The Hastings Center Report*, 29(5), S1–S22. doi:10.2307/3527746
- Powell, C. (2000). The current state of prenatal genetic testing in the United States. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 44–53). Washington, D.C.: Georgetown University Press.
- “Prenatal Tests.” (n.d.). Retrieved July 17, 2012, from http://kidshealth.org/parent/system/medical/prenatal_tests.html
- Press, N. (2011). Assessing the expressive character of prenatal testing: the choices made or the choices made available? In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 214–233). Washington, D.C.: Georgetown University Press.
- Rapp, R. (1988). Chromosomes and communication: the discourse of genetic counseling. *Medical Anthropology Quarterly*, 2(2), 143–157.
- Rapp, R. (1999). *Testing women, testing the fetus: The social impact of amniocentesis in America*. Psychology Press.
- Saxton, M. (2000). Why members of the disability community oppose prenatal diagnosis and selective abortion. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 147–164). Washington, D.C.: Georgetown University Press.
- Scott, J. B. (2003). *Risky rhetoric: AIDS and the cultural practices of HIV Testing*. Carbondale: SIU Press.
- Seavilleklein, V. (2009). Challenging the rhetoric of choice in prenatal screening. *Bioethics*,

23(1), 68–77. doi:10.1111/j.1467-8519.2008.00674.x

Shakespeare, T. (1999). “Losing the plot”? Medical and activist discourses of contemporary genetics and disability. *Sociology of Health & Illness*, 21(5), 669–688.

Shildrick, M. (2004). Genetics, normativity, and ethics: Some bioethical concerns. *Feminist Theory* 5(2), 149–165.

Stowe, M. J., Turnbull, H. R., Pence, R., Rack, J., Schrandt, S., & Laub, L. (2007). The importance of attitudes toward and understanding of disability and science in the age of genetics. *Research and Practice for Persons with Severe Disabilities*, 32(3), 190–206.

Tremain, S. (2006). Reproductive freedom, self-regulation, and the government of impairment in utero. *Hypatia*, 21(1), 35-53.