

A closer look at disability: a parent's commentary

Maria Baranowski MSc, RD[†]

Abstract

Disability has long been considered as a reason to grieve. Historically, the lived experience of individuals categorized as having a disability, and their families, has not been meaningfully considered or accurately understood. Individuals characterized with a disability have been institutionalized, educated separately, and isolated from the majority of the population throughout human history. These actions have impacted relationships in all environments. As beliefs and values have evolved over time, the traditional meaning and culture of disability has been challenged and is beginning to change. At the same time, prenatal screening and testing now provides information to potential parents about the likelihood of their child being born with a condition that is characterized as a disability. Some research suggests that increased access to this type of data is associated with a reduction in the prevalence of some conditions characterized as disability within our population. So, while there is advocacy for inclusion and to consider and treat individuals characterized with a disability the same as those without a diagnosis, there also appears to be selective termination of some lives that are predicted to include disability. Now is an opportunity to reconsider our own assumptions about disability, and a plurality of perspectives, especially those perspectives that we perceive to be most different than our own.

Keywords: disability, prenatal screening, pregnancy, social model of disability

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Introduction

Advanced medical technology and greater access to prenatal care have provided potential parents with information about their offspring that was unattainable in previous generations. The following is a commentary about the potential consequences of greater access to this type of information specifically, as it applies to predicting what is characterized as disability. For example, de Graaf and colleagues recently observed an association between increased population reduction rates of Down syndrome and the introduction of prenatal screening in almost all European countries. They reported an estimated 27% population reduction rate of individuals born with Down syndrome living in Europe.¹ The advocacy group, "We Need a Law," suggests that increased access to prenatal testing and genetic counseling is associated with a presumption that parents will select abortion.² This opinion has been shared and discussed by others.³⁻⁶

This presumption may be partly explained by the traditional, yet largely uncritiqued, application of the Kubler-Ross grief model (1969) in the interpretation of

a parents' experience having a child born with a disability, even though the model was designed to describe the process of dying and death, not disability.⁷ This was not its original intention nor may accurately reflect a parent's lived experience. Many professionals have been taught that parents experience the stages of grief outlined from Kubler-Ross' work on death and dying when they learn of their child's disability.⁸ Their lived experience has not been significantly considered or represented and consequently, the traditional understanding and perception of disability may not be accurate. Notably, Kearney and Griffin reported that parents of children born with a disability shared that they experience feelings of joy from their lived experience with their child, but sorrow from their experiences with professionals and others.⁹ Other parents have also shared their positive experiences.^{3,4}

Disability itself has been historically portrayed as the lack or absence of a desirable quality or ability and characterized as inherently negative or unwanted. These individuals and their families have faced discrimination, institutionalization, segregation, and isolation throughout human history. Societal beliefs and atti-

*Correspondence to: baranowm@myumanitoba.ca

[†]Department of Community Health Sciences, University of Manitoba

tudes towards individuals characterized with disability and their families have changed slowly over time; it was not until 2006 when the UN Convention on the Rights of Persons with Disabilities was adopted, recognizing individuals with disabilities as active members of society.¹⁰

Thesis statement

The purpose of this commentary is to explore how the provision of information regarding prenatal disability screening and its results may influence the experience and perceived choices of the recipient, particularly in relationships where there is a power imbalance, such as between a healthcare professional and patient. Not only are patients dependent on the accurate interpretation of test results by their healthcare provider, especially when the information may be used to inform decisions that may have significant and long-term consequences, they may also be influenced by the delivery of information about prenatal disability screening and test results. Demonstrations of compassion and sensitivity, as well as consideration to parents' lived experience, are important values to guide healthcare providers' behaviours towards parents during this time.

Arguments

In more recent times, advanced prenatal screening has provided parents with access to additional information about the probability of having a child born with certain disabilities. There may be a multitude of factors parents consider when deciding how to manage a pregnancy, and prenatal disability screening results may represent one of many factors for some parents. Due to its potentially significant influence on parents' perceived choices, the importance of the way in which an individual receives prenatal screening test results has been explored. In their systematic review of qualitative studies that explored parental responses to a prenatal diagnosis, Lou and colleagues reported that empathetic and informative interactions with clinicians were a key component of a parent's experience in an unexpected and vulnerable moment. For example, prospective parents requested clear, specific, detailed, and written information to reflect upon at a later time.¹¹ From their review, Lou et al. also found that parents noted when their feelings were acknowledged, and each word, gesture, and expression of support from professionals.¹¹ Nelson Goff and colleagues found no difference between groups in their comparative study of parent's experiences receiving the initial Down syndrome diagnosis pre- or postnatally, and reported that parents in both groups shared that they received a lack of current and accurate information, and little or no compassion or support, from medical professionals.¹² From their interviews with prospective parents, Ashtiani and colleagues propose a mechanism that may determine whether parents perceive their experience of receiving a medical genetic diagnosis as positive or negative. A

few examples from their findings suggest that a positive experience was reported when parents felt prepared to receive the information, hope was conveyed by the medical professionals, and less jargon was used during the appointment.¹³ Demonstrating empathy towards prospective parents who may be unprepared to receive life-changing information, speaking clearly and simply about the facts of the diagnosis, including things that are not known, providing a safe space for parents to express their reaction, and planning for future follow-ups, may be helpful strategies to create a more positive experience.

Hulda Hjartardottir, head of the Prenatal Diagnosis Unit at Landspítali University Hospital in Iceland, a country where it has been reported that only 2 or 3 children are born with Down syndrome per year, shares that "We try to do as neutral counseling as possible, but some people would say that just offering the test is pointing you towards a certain direction."¹⁴ It may also be important to understand and convey that disability is not synonymous with disease or poor health, and that the former does not necessarily infer the latter.¹⁵ For example, the Canadian Down Syndrome Society lists some health concerns associated with Down syndrome on their website while also highlighting that these health problems can occur in individuals without Down syndrome and can be successfully managed and treated.¹⁶ While it is important for parents to be informed of their child's potentially increased risk for some medical conditions from healthcare professionals, it is also important to acknowledge their inherent position of power in translating scientific evidence, and to frame these facts within a greater context to ensure that parents are interpreting the information accurately and are not left feeling disempowered.

Conclusion

The absence of diagnosis of disability at birth does not preclude one from experiencing disability throughout their own life, or in that of a loved one. In fact, based on 2010 world population estimates and 2004 disability prevalence estimates, the World Health Organization reports over a billion people (approximately 15% of the world's population) are living with a disability.¹⁷

It is possible to marvel at the advancements in medical technology while also acknowledging its potential for error and limitation. Recognition of the inherent power imbalance between healthcare professionals and their patients is essential, especially when experiencing an unexpected event. There is great responsibility on those in positions of influence to deliver information in a balanced and sensitive manner.

In light of the reduced population prevalence rate of Down syndrome reported by de Graaf and colleagues, we may choose to re-examine our societal beliefs about how we perceive those characterized with disability.¹ From the perspective of the social model of disability, it may be the environment and not the individual, in need of improvement.¹⁸ Future research on the impact

of decreased prevalence of live births of those born with disability associated with increased prenatal screening may be warranted. What is the impact on parents who decide to continue their pregnancy, and on those who decide to terminate their pregnancy? What is the impact on individuals currently living with disability? What is the impact on social norms, advocacy efforts, and social inclusion?

The way in which we perceive one another, especially those we believe are most different than ourselves, may not always be based on accurate information or lived experience. Consideration of a plurality of perspectives through examination of scientific evidence and exploration of lived experience may challenge us all to reconsider what is characterized as disability.

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