



The expressivist objection to prenatal testing: The experiences of families living with genetic disease



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ARTICLE INFO

Article history:

Received 17 April 2013

Received in revised form

10 February 2014

Accepted 13 February 2014

Available online 14 February 2014

Keywords:

UK

Disability rights

Expressivist objection

Qualitative

Genetic risk

Reproductive decision making

Spinal Muscular Atrophy

ABSTRACT

The expressivist objection to prenatal testing is acknowledged as a significant critique of prenatal testing practices most commonly advanced by disability rights supporters. Such writers argue that prenatal testing and selective termination practices are objectionable as they express disvalue not only of the foetus being tested, but also of disabled people as a whole, by focusing exclusively on the disabling trait. While the objection has been widely critiqued on the basis of its theoretical incoherence, this paper highlights the way in which it, nevertheless, is a significant mediator in decisions around the use of reproductive genetic technologies. By drawing on 41 in-depth qualitative interviews (drawn from a sample of 61) conducted in the UK between 2007 and 2009 with families and individuals living with a genetic disease, Spinal Muscular Atrophy (SMA), this paper highlights the ways in which expressivist objections feature prominently in the reproductive decisions of families living with SMA and the significant emotional burden they represent. While the literature on the expressivist objection has focused on the reproductive decisions of those undergoing prenatal testing for a condition of which they have little (or no) prior knowledge, the context of intimate familial relationships and extensive experience with the tested-for condition fundamentally alters the nature and impact of expressivist objections within families living with an inheritable condition. By focussing on the reproductive decisions of families living with SMA and their strategic management of the expressivist objection, this paper will address the call, made primarily by disability rights supporters, for 'experientially based' (as opposed to medical) information about the tested-for disability to be made available to would-be parents considering selective termination. It will be argued that parents' experiential knowledge of the tested-for disability can, in fact, amplify expressivist objections to prenatal testing, and thus paradoxically constrain, rather than facilitate, reproductive decisions.

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1. Introduction

As the capacities of reproductive genetic technologies have expanded in recent years, so too have the number and nature of reproductive decisions facing would-be parents. While such technological advancements have been heralded as increasing the reproductive autonomy of such parents, the ways in which these decisions are actually made and experienced have come under scrutiny by researchers, who have problematized the notion of 'choice' in which the technologies are couched, instead pointing to the potentially constraining effects of the technologies (Lippman, 1991). The so-called 'expressivist objection' has been amongst such critiques of prenatal testing. The term 'expressivist objection'

(hereon referred to as the 'EO') was coined by Buchanan (1996) and refers to:

The claim...that...the commitment to developing modes of intervention to correct, ameliorate, or prevent genetic defects expresses (and presupposes) negative, extremely damaging judgements about the value of disabled persons.

(Buchanan, 1996: 28)

As such, the EO, as a critique of genetic testing practices, has been most often advanced by disability rights supporters (e.g. Parens and Asch, 2000). Such disability rights supporters have questioned prenatal testing and screening practices (and the subsequent offer of selective termination of pregnancies where genetic differences are detected) on the basis that they not only express a negative valuation of the foetus being tested, but also of the lives of

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people living with disabilities more generally (Parens and Asch, 2000; Saxton, 2000). Following this argument, the selective termination of a pregnancy is considered objectionable on the grounds that the particular trait (the disability) comes to represent the entire foetus, rendering immaterial the complexity of all its other traits (Asch, 2000; Saxton, 1997).

While the theoretical coherence of the EO, and in particular its claim that prenatal testing practices are capable of 'expressing' any message, has been called into question by various scholars, both within and without the disability rights community (Shakespeare, 2006), there remains a lack of empirical evidence exploring its impact, particularly amongst people with disabilities (Madeo et al., 2011: 1779). A select number of studies have explored the attitudes of people with the inheritable disabilities to genetic testing (e.g. Middleton et al., 1998; Gollust et al., 2003), and more recently, researchers have considered how the EO may be shaped by, and managed within, the broader context of the disabled person's family, and familial experiences with the condition (Barlevy et al., 2012; Rasperry et al., 2011; Helbig et al., 2010; Kelly, 2009). While critics have argued that prenatal testing and termination decisions are usually made in the private sphere and, as such, are incapable of communicating negative messages to disabled people (Murphy, 2011), families can be described as arenas of 'reproductive accountability' and 'public' reproductive decision-making (Burgess and D'Agincourt-Canning, 2001). They are sites in which reproductive decisions may be subject to family scrutiny, and where there can be a (felt) need to justify decisions taken (Downing, 2005; Cox, 2003). Moreover, disabled people and their families usually approach genetic testing decisions equipped with extensive 'experiential knowledge' (Abel and Browner, 1998) about the condition being tested for (Kelly, 2009; Rasperry et al., 2011). This experiential knowledge, as well as the familial context of reproductive decision-making fundamentally alters the nature and power of the perceived messages expressed by prenatal testing technologies. Yet, a clear distinction between *this* context and that of testing decisions made by the general population with no prior knowledge of the tested-for condition has not been widely acknowledged within the EO literature, in spite of the different implications these scenarios have for experiences of the EO. Indeed, the experiences and views of disabled people and their families living with an inheritable condition have a lot to offer debates around the EO. Where this issue has been explored in the literature, the focus of the studies has either exclusively been on those individuals diagnosed with the condition themselves (e.g. Helbig et al., 2010), or their family members (e.g. Rasperry et al., 2011; Kelly, 2009) with very few studies addressing both (e.g. Barlevy et al., 2012). Consequently, the question of how differing ways of knowing genetic disease inform reproductive decision-making and perceptions of the EO within families has been hitherto neglected. Such an analysis can address the question of how differing levels of experiential knowledge of the condition being tested for can impact on perceptions of the expressive potential of testing decisions, and add to policy debates regarding the value of such knowledge in prenatal testing decisions.

This paper will address the above outlined gap in the literature by drawing on an in-depth interview study (61 interviews with 59 participants) with people living with an inheritable condition, Spinal Muscular Atrophy (SMA) in their family (Boardman, 2010). Through the accounts of a sub-sample ($n = 41$) of these participants, I will argue that while the theoretical basis of the EO may be disputed, its existence and 'felt presence' amongst families living with SMA significantly influences the way they approach- and manage- prenatal testing decisions. For such families, the EO not only has a significant- and sometimes burdensome-emotional impact, it was also described as having a constraining effect on

reproductive decision-making, which had to be carefully negotiated.

2. The expressivist objection

Disability rights supporters have been amongst those who have most passionately advanced the EO as a way to critique the discriminatory attitudes and beliefs they deem to underpin prenatal testing practices as well as the messages they perceive to be sent by them to disabled people (Parens and Asch, 2000; Saxton, 2000; Wendell, 1996). In particular, disability rights supporters have critiqued the incompatibility of prenatal testing technologies and the practices surrounding them with the unconditional acceptance of children, irrespective of their genetic traits. To test for disabling traits in the foetus, and then to base selective termination decisions upon this information, is, according to Asch (2000), to allow the disabling trait to 'trump' all other (as yet unknown) characteristics of the foetus. For many disabled people, this prioritising of disability over and above all other traits is echoed in their daily experiences in a profoundly disablist society:

As with discrimination more generally, with prenatal diagnosis a single trait stands in for the whole, the trait obliterates the whole. With both discrimination and prenatal diagnosis, nobody finds out about the rest. The tests send the message that there's no need to find out about the rest.

(Asch, 2000:13)

For disability rights supporters, the medical profession (inadvertently or otherwise) reinforces and recycles these negative messages through the processes of prenatal diagnosis and selective termination by counselling prospective parents (following a positive prenatal diagnosis) only on the medical complications associated with that disability, while usually ill-equipped to offer insight into the daily realities of life with that particular disability, as Williams et al. (2002) demonstrated in relation to Down's Syndrome counselling. For feminist writers as well, the very existence and consequent routinisation of prenatal testing technologies suggests an implicit responsibility to use them (and thereby to test and terminate affected fetuses) (Lippman, 1991; Markens et al., 2010; Clarke, 1991), potentially making it harder for those parents who wish to continue with an affected pregnancy to justify their decision as 'responsible' (Barlevy et al., 2012: 36).

These critiques of prenatal testing and screening practices, however, have not been universally accepted. Within the field of disability studies itself, the EO has come under harsh scrutiny and there is an acknowledgement that the EO is not supported by the whole of the disability community, many of whom see the EO as an over-simplification of their diverse views on this topic. However, writers such as Shakespeare (2006) have argued that to assume that prospective parents wish to terminate pregnancies affected by disability primarily on the basis of ignorant, prejudiced or otherwise negative attitudes towards disability is to simplify what are often highly complex and emotionally charged decisions. Indeed it is not, Shakespeare (2006) points out, a contradiction to both terminate a pregnancy affected by disability (for example, if a person feels that they could not provide the additional resources required to raise a disabled child), and to simultaneously uphold respectful and supportive views of disabled people within society. Indeed, for many disability rights supporters, the concerns of EO proponents with the decision-making processes of prospective parents and the 'messages' these decisions are deemed to send not only vilifies would-be parents but also diverts attention away from the social and political context in which reproductive genetic

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