

Received: 15 February 2020 | Revised: 27 April 2020 | Accepted: 28 April 2020

DOI: 10.1111/apa.15336

ACTA PAEDIATRICA PERSPECTIVES

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Whose life is worth preserving? Disabled people and the expressivist objection to neonatology

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Funding information

Wellcome Trust, Grant/Award Number: 203384/Z/16/Z

In an age of expansive genomic medicine, the findings of genetic sequencing techniques (whole genome/exome/mtDNA) are increasingly being factored into decisions about the treatment of critically ill neonates. Yet, such decisions remain highly ethically fraught.¹ Neonatologists are generally familiar with the ethical complexity of such decisions and the value judgements about 'worthwhile life' inherent within them. However, they are far less exposed to the views and life experiences of adults and families who currently live with the genetic conditions, seen in neonatal intensive care, albeit in milder forms (eg, SMA types II- IV). The insights of this group have much to offer an understanding of 'worthwhile life' in the context of treatment (and non-treatment) of critically ill babies, yet their voices are seldom heard within these debates. This paper highlights how these views can be illuminating for neonatologists by drawing on a recent research study with adults living with a range of genetic conditions.²

Adults living with a variety of genetic conditions in the UK (including Spinal Muscular Atrophy, Haemophilia, Thalassaemia, Fragile X Syndrome and Cystic Fibrosis), as well as their family members, were recently included in a large research project exploring attitudes towards population-wide genetic screening programmes.² The resulting interviews (n = 130) and surveys (n = 1500) explored perspectives on 'worthwhile life'; how the availability of genetic screening might have influenced their own reproductive decisions, and ultimately whether they would want to see the eradication of their condition through genomic interventions.

The data emerging from this study has produced a rich and varied picture of the views of this heterogeneous group. Overwhelmingly, the theme of ambivalence has characterised their responses to genomic medicine and the futures for reproduction and genetic

disease suggested by it. This ambivalence stems, in a large part, from the lived realities of these conditions.

Participants across all condition groups drew attention to the plethora of factors that contributed to their daily lives, the most significant of which typically had little to do with the genetic condition itself, but instead, the social and environmental conditions through which it was experienced.³ Social stigma, lack of adapted environments and the unavailability of financial/practical support, for example, all emerged as factors that could be as detrimental to life quality as the condition. Furthermore, the study found little evidence of the assumed inverse relationship between phenotype severity and poor life quality. Adults with type II SMA, for example, overwhelmingly reported more positive life experiences than their counterparts with clinically less severe forms of the condition (types III and IV). Alex, an adult with type II SMA reflected on her own, and her sister, Penny's, response to life with SMA (Penny was diagnosed with type III SMA) when she commented;

Everyone expects me to be the bitter one because I'm type II and she's type III. I've never been able to walk, yet she has. But she's the one who hates having SMA ... she's had to watch herself decline, whereas I never had it in the first place. We have completely different outlooks.

(Alex, 22, SMA type II)

Identity politics played a significant role in this finding; participants with early onset conditions were more likely to view their condition as part of their personal identity and to have set their lives up around its existence than those with later onset/degenerative conditions.

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However, this is not to say that physical suffering did not also feature in these families' accounts. Conditions that were significantly life-reducing, degenerative and/or that involved periods of illness, pain and/or hospitalisation were notably mentioned as features that dramatically and negatively impacted 'worthwhile' life. However, it is to say that these participants nevertheless still situated this suffering within a much wider social and experiential context.⁴

For neonatologists who must make judgements about anticipated life quality for critically ill neonates, this social and personal framing is largely elusive. Their judgements must instead be grounded solely in the pheno- and genotype presentation of the infant, reducing their transferability to the lived experiences of adults with genetic disabilities reported here. This reductivism, however, also leaves their judgements more vulnerable to what has been termed the 'expressivist critique', a notion that has impacts extending beyond neonatal intensive care.

The 'expressivist critique' is an idea that was originally developed by disability rights supporters in response to prenatal testing and selective termination.⁵ The argument follows that to selectively terminate a pregnancy based on a genetic trait is to express not only a negative valuation of that trait, but also the lives of people living with that trait. When applied to neonatology, expressivist objections would follow that a decision to allow an infant to die communicates an unequivocal negative appraisal of the value and quality of that child's life, which could logically be extended to the lives of others who share its condition.

Whilst widely cited, however, it is important to note that the expressivist critique has not been universally accepted, being viewed critically from both within and without the disability rights community. Commentators argue, for example, that it should not be considered a contradiction to both terminate a pregnancy affected by a genetic condition (eg, due to inadequate resources to care for a child with high support needs) whilst simultaneously upholding the value of people with those needs.⁶ However, with neonatology decisions being so tightly focused on the clinical implications of the condition, devoid of the wider contextual and interpersonal factors that are a feature of termination decisions, this defence becomes harder to sustain.

Whether or not the theoretical robustness of the expressivist critique is accepted, however, is, in many ways, irrelevant. There is clear evidence that it is perceived as relevant to, and has significant impacts on, the lives of many people who live with genetic disease.⁷ One participant with SMA, for example, reflected on the highly publicised 2006 'baby MB' case (an infant with SMA whose doctors wanted to withdraw life-sustaining treatment) when she commented;

Every time an SMA baby is aborted or allowed to die, it sends a message to all of us that society thinks it would have been better had we not existed at all.

(Rosie, 32, SMA Type II)

Rosie's view highlights the way in which her identification with baby MB, who shared her condition, had impacts that stretched

beyond the intensive care unit. The doctors' desire to withdraw treatment from baby MB was interpreted by Rosie as a public, and damning, social commentary on the value of life with SMA. This view came to be highlighted by the media as one shared by other people with SMA.⁸ Indeed, the implicit association between 'disability' and 'suffering' that is underscored by these types of decisions is one that the disability rights movement has worked hard to resist. Social model of disability theorists, for example, argues that the amalgamation of disability and suffering detracts focus from the social and environmental factors that create, or at least contribute to, disability, by instead foregrounding individuals with medical conditions as the real 'problems'.⁹ At a point in time where debates about the treatment of critically ill neonates are increasingly moving into the public sphere, facilitated by the proliferation of social media, the ramifications of these decisions for disabled people appear set to only become more widespread in the future.

Given this significance, it is imperative that the judgements of neonatologists incorporate an understanding of the lived realities of disability, as reported by disabled people themselves. The social world invariably, and often surreptitiously, influences what neonatologists consider 'worthwhile life'. In turn, their judgements feed back into, and directly influence, that same social world. As such, neonatologists need to engage in continuous reflexive practice.

This reflexivity may usefully include a consideration of the role that personal experience with health and disability plays in framing the sorts of health states that neonatologists consider intolerable in others, and, ultimately, the decisions they make about treatment withdrawal or continuation. In addition, they may also benefit from engagement with the disability community, either directly or at the very least through the published literature, to explore these concepts. Research demonstrates that disabled people consistently rate their quality of life higher than the people around them do,¹⁰ highlighting the need to disentangle clinical definitions of disease severity from the lived realities of the condition they are assumed capable of capturing (eg, Alex). The findings of these studies clearly demonstrate how critical it is to explore the lived experiences of disabled people within their own frames of reference. Their stories can provide insights into the way that disability and 'suffering' are interpreted and experienced within a broader social and personal context, factors that increasingly need a place within neonatology. Indeed, whilst the introduction of genomic medicine to neonatal intensive care may bring new insights to ethically complex decisions, it is nevertheless also important to consider the gaps that this ever-tighter focus on clinical information opens up, and to think creatively about they can be both identified and addressed.

CONFLICT OF INTEREST

Dr Felicity Boardman has no conflicts of interest to declare.

FUNDING INFORMATION

The research presented in this paper is funded by a Wellcome Trust Investigator Award. Grant ref: 203384/Z/16/Z.

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