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Experience as knowledge: Disability, distillation and (reprogenetic) decision-making

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ABSTRACT

'Experiential knowledge' is increasingly recognised as an important influence on reproductive decision-making. 'Experiential knowledge of disability' in particular is a significant resource within prenatal testing/screening contexts, enabling prospective parents to imagine and appraise future lives affected by disability. However, the concept of 'experiential knowledge' has been widely critiqued for its idiosyncrasy, its impermanence and consequently its perceived inferiority to (medical) knowledge. This paper explores some of these key critiques of experiential knowledge through an analysis of its constitution and uses in the context of reproductive decision-making. Seventeen UK-resident women with Spinal Muscular Atrophy (SMA), or with SMA in their family, took part in two in-depth interviews: one in 2007–9 and the other in 2013–4. By comparing and contrasting these women's accounts at two time points, this paper demonstrates the stark contrast between 'lived experience' of SMA (the visceral everyday realities of life with the condition) and the various way(s) this experience was transformed into, and presented as, 'knowledge' through the processes of making, and accounting, for reproductive decisions. The analysis highlights that multiple, distinct and sometimes competing experiential frameworks are used to conceptualise SMA across time and context. However, rather than evidence of its fallibility, this finding highlights that 'knowledge' is an inappropriate vessel with which to capture and transfer 'experiential knowledge'. Rather, we need to consider how to value such insight in ways that harnesses its inherent strength without leaving it vulnerable to the epistemological critiques attracted by labelling it 'knowledge'.

1. Introduction

Experiential knowledge, that is, knowledge gained through either 'embodied' (direct bodily experience) or 'empathetic' (knowledge gained through close emotional ties with others) experience of a phenomenon (Abel and Browner, 1998), has been increasingly acknowledged in the health and social science literature as a significant body of knowledge (Prior, 2003; Baillergeau and Duyvendak, 2016; Caron-Finterman et al., 2005) and one of substantial influence in the context of health care decision-making (Bulme, 2016; Lippman, 1999; Markens et al., 2010; France et al., 2011). The decline of paternalistic models of medicine, the paralleled increase in, and emphasis on, personalised medicine and patient organisations together with the gains made by both the feminist and disability rights movement since the 1970s have all contributed to the expanding value placed on the realm of the experiential as a resource with which to supplement, supplant or challenge medical knowledge (Abel and Browner, 1998; Frank, 1995; D'Agincourt-Canning, 2005; Williams and Popay, 1994; Bulme, 2016; Baillergeau and Duyvendak, 2016; Rabeharisoa et al., 2014; Britten and Maguire, 2016; Boardman, 2014).

Within the domain of reproduction, the development of increasingly sophisticated reproductive technologies (such as NIPT), and the acceleration of advances in genomic medicine have created a context in which the role and value assigned to experiential knowledge is gaining significance. Would-be parents, for example, are being increasingly called upon to make reproductive decisions based on 'risk factors' (rather than definitive diagnoses), and in relation to increasingly obscure conditions with uncertain prognoses (Novas and Rose, 2000; McClaren et al., 2008). It is against this backdrop of burgeoning probabilistic reprogenetic information, yet also an increased use of reproductive genetic technologies, that experiential knowledge has gained status as a tangible resource with which to navigate complex decisions that

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have uncertain outcomes (Boardman, 2014). The majority of studies that explore experiential knowledge in the domain of reproduction have focused on women's embodied experiences of pregnancy and how these are brought to bear on decision-making (e.g. Lippman, 1999; Katz Rothman, 1984; Markens et al., 2010; Abel and Browner, 1998). However, more recently, 'experiential knowledge of disability' – that is, the insights born out of the daily realities of living with a disabling condition-has also been acknowledged as another form of experiential knowledge that may exist independently of, or co-exist with, women's embodied experiences of pregnancy (France et al., 2011; Etchegary et al., 2008; Boardman, 2014, Boardman et al., 2017a).

'Experiential knowledge of disability', it is argued, is of particular relevance in the context of prenatal screening, testing and selective termination decisions as it may be used as a resource with which to imagine- and appraise-the nature and quality of future lives affected by that condition (Boardman, 2014; Dudding et al., 2000; Sawyer et al., 2006; Polnay et al., 2002; Raspberry and Skinner, 2011; France et al., 2011; Etchegary et al., 2008). For this reason, much like women's bodily experiences of pregnancy, experiential knowledge of disability has been ascribed political value (Bricher, 1999; Parens and Asch, 2000; Asch and Wasserman, 2015) and regarded by many-particularly disability rights supporters-as the counter-weight to medicalised representations of disability in screening and testing contexts (Williams et al., 2002; Potter et al., 2008), offering alternative insights into life with the condition that are deemed to fall beyond the remit of reproductive genetic medicine (Ahmed et al., 2007).

Whilst this body of literature highlights the growing acknowledgement and various uses of 'experiential knowledge of disability' in reproductive contexts (Etchegary et al., 2008; France et al., 2011), it nevertheless remains a concept which is poorly defined and understood. Indeed, many commonly accepted understandings of experiential knowledge have cast it primarily in terms of its similarities and differences to medical knowledge, in order to either highlight its deficiencies (Prior, 2003) or to demarcate its contrasting areas of strength (Wynne, 1996). Whilst this comparison has been pivotal to the acceptance of experiential knowledge as a site of alternative expertise, however, this framing nevertheless also relegates the domain of the experiential to a state of perpetual dependence; as 'always-in-relationship-to' medical knowledge, ever vulnerable to critiques of deficiency, lack and inferiority.

This paper considers this position and the role and value of 'experiential knowledge of disability' as it is produced by and through accounts of reproductive decision-making. Drawing on 34 longitudinal in-depth interviews, the presented analysis explores the reproductive attitudes and decisions of 17 women clinically defined as 'at risk' of transmitting a neuromuscular condition, Spinal Muscular Atrophy (SMA). Two interviews were conducted with each participant (with a 6/7 year interval) in order to capture the shifting nature of their lived experience of SMA and to chart changes in their reproductive views and decisions during this time. By including two time points, and offering a comparison between them, this paper outlines the stark contrast between the cacophonous and ever-changing world of lived experience and the much more static and ordered realm of 'experiential knowledge'. Finally, this paper will offer a critique of the notion that 'knowledge' is the appropriate prism through which to view and present experience. Through doing so, the various ways in which aspirations to knowledge status may paradoxically undermine, rather than bolster, the status of the experiential will be considered, highlighting the need for ongoing critical attention in this area.

1.1. Spinal Muscular Atrophy and reproductive genetics

After Cystic Fibrosis, SMA is the most common (potentially fatal) autosomal recessively inherited condition in the UK, meaning it is a single gene disorder requiring two carrier parents to transmit. SMA affects approximately one in every six thousand newborns in the North West European population (Dreesen et al., 1998). It is a neuromuscular condition characterised by generalised, and often severe, muscle weakness. SMA has been sub-categorised into distinct clinical 'types' (I-IV) with different presentations, ages of onset, severity of muscle weakness and prognoses ranging from early infantile death in the case of type I to adult-onset muscle weakness in adulthood in type IV (Dubowitz, 2008).

In order to understand the reproductive dilemmas faced by families living with SMA, it is firstly necessary to understand its typical mode of inheritance. It is estimated that between 1:40 and 1:60 of the general population are 'carriers' of SMA (i.e. they can transmit the condition but have no symptoms) (Wirth, 2000). When two carrier parents reproduce, they have a:

- 25% chance of a child who will have SMA.
- 50% chance of a child who will be an asymptomatic carrier.
- 25% chance of a child that will be neither a carrier nor have SMA.

Prenatal testing, Pre-Implantation Genetic Diagnosis (PGD) and cascade carrier screening (the genetic testing of family members of people with SMA) are all available on the NHS for families with a confirmed history of SMA.

2. Methods

Interviews were conducted at two time points.

2.1. Phase 1 (P1): in-depth interviews, 2007-9

The first round of interviews was conducted 2007–2009 as part of a larger study of sixty-one participants with SMA in their family (Boardman, 2010, 2014). The interviews were designed to elicit participants' stories of life with SMA and a discussion of their views around, and (intended) uses of, reproductive genetic technologies. Participants were recruited through the main support group for families living with SMA in the UK- SMA Support UK. Participants were recruited using a variety of channels; through the group's annual conference, advertisements in their publications, personal contacts and snowball sampling. Two participants were also recruited through disability organisations. The 17 participants whose data is reported on in this paper were all recruited through SMA Support UK.

Interviewing took place through a variety of channels (telephone, face-to-face and email), allowing for participant preference and practical constraints. Telephone and face-to-face interviews lasted, on average, for 70 minutes, and email interviews took place over periods lasting from three weeks to eight months. Email interviewing is a method of interviewing whereby interview questions and answers are exchanged electronically (Burns, 2010). This method of interviewing allowed participants to answer in instalments, at dates and times of convenience (McCord and Schwaber Kerson, 2006). Use of this method facilitated participation due to the potentially emotionally demanding nature of the interview and because the majority of participants were caring for young children and/or managing complex disabilities.

2.2. Phase 2 (P2): in-depth interviews, 2013-4

The second round of interviews took place 2013–14, some 6/7