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Knowledge is Power? The Role of Experiential Knowledge in Genetically ‘Risky’

Reproductive Decisions

Abstract: Knowledge of the condition being tested for is increasingly acknowledged as an important factor in prenatal testing and screening decisions. An analysis of the way in which family members living with an inheritable condition use and value this knowledge has much to add to debates around whether and how this type of knowledge could be made available to prospective parents facing screening decisions. This paper reports on in-depth interviews with sixty-one people (conducted 2007-9), with a genetic condition in their family, Spinal Muscular Atrophy (SMA). Many participants described their intimate familial knowledge of SMA as offering them valuable insights with which they could imagine future lives. Other participants, however, found themselves trapped between their experiential knowledge of SMA and their (often) competing responsibility to maintain the wellbeing of their family. Still others established a ‘hierarchy’ of knowledge to rank the authenticity of different family member’s accounts of SMA in order to discredit, or justify, their decisions. This paper highlights the way in which experiential knowledge of the condition being tested for cannot be unproblematically assumed to be a useful resource in the context of prenatal testing and screening decisions, and may actually constrain reproductive decisions (195 words).

Word Count: 7,496 + 500 (2 tables) = **7,996 words**

Introduction

‘Experiential knowledge’ is a term that has been used by various researchers to account for the ‘experiential and particularistic’ (Abel and Browner, 1998: 310) ways of knowing the world that individuals draw upon to assess risks, evaluate expert knowledge and make decisions, particularly in relation to health. In the context of reproductive decision making, experience of the disability or condition being tested for is increasingly recognised as an important source of knowledge that prospective parents draw upon to evaluate reproductive risks and make informed decisions (Etchegary et al., 2008; France et al., 2011). For disability rights supporters, this form of knowledge has political significance in a social context that largely devalues the lives of disabled people and offers predominantly medical model interpretations of life with disability in prenatal testing contexts (Shakespeare, 1999; Williams et al., 2002; Parens and Asch, 2000). As prenatal screening and testing practices expand, increasing the number and nature of decisions to be made by would-be parents, the need to understand the role that experiential knowledge plays in informing such decisions appears set to become ever more important. The recent moves towards the introduction of genetic screening for a host of recessive conditions (Human Genetics Commission, 2011), together with the introduction of newborn screening programmes, mean that in the future more parents will be making screening and testing decisions for conditions of which they have no prior experience or knowledge. Therefore, understanding the role and status of experiential knowledge of disability in the context of prenatal testing and screening, and its usefulness to prospective parents, is now critical.

‘Experiential knowledge’ is a term that has been used differently by different researchers. Whilst for some, experiential knowledge is a term synonymous with ‘lay knowledge’ (Caron-Fintermann et al., 2005) - a concept already well-researched within medical sociology (Wynne, 1996; Popay and Williams, 1996) - for others, it has specific defining characteristics. Borkman (1976), for example, outlines two key features of experiential knowledge: 1) it is knowledge based upon the experiences of an individual and 2) it is knowledge that is highly valued by that individual as it has been acquired through the individual’s direct interaction with the physical, social and intellectual world (Borkman, 1979: 450). For Borkman (1979), experiential knowledge has pragmatic uses; it is translated into strategies and methods for living with a particular problem, which is then pooled with others, typically in the context of a self-help organisation. More recently, however, there has been a move away from a definition of experiential knowledge as a template for action, and instead an emphasis on its contextual, subjective, unconscious and emotional properties. Abel and Browner (1998) differentiate two distinct types of experiential knowledge: ‘embodied’ and ‘empathetic’. Embodied knowledge refers to personal perceptions of bodily experiences and sensations (e.g. pregnancy), whereas empathetic knowledge is derived from close association with others living with a particular experience (e.g. care giving). Thus, ‘one derives from direct sensory experience, the other from close emotional ties between individuals’ (Abel and Browner, 1998: 315). These definitions have been taken up by different researchers to explore how proximity to the experience in question creates different ways of knowing (e.g. D’Agincourt-Canning, 2003; Etchegary et al., 2008).

Whilst researchers have suggested various ways in which experiential knowledge can be defined, acquired and used, there nevertheless appears to be

agreement in the literature that it is a key form of knowledge that is drawn upon in the context of decision making and risk assessment. Indeed, the role of experiential knowledge in informing genetic risk perceptions and genetic testing decisions has been analysed for conditions as diverse as Cancer (Hallowell, 2006; D'Agincourt-Canning, 2005), Huntington's Disease (Downing, 2005; Cox, 2003), X-linked conditions (Parsons and Atkinson, 1992; Kay and Kingston, 2002) and Cystic Fibrosis (Wertz et al, 1992; Evers-Kiebooms et al., 1988). More recently, however, its role in prenatal testing and screening decisions has been emphasised (Etchegary et al., 2008; France et al., 2011).

For disability rights supporters, experiential knowledge of the tested-for condition is regarded as having political significance. Such writers have argued that screening and testing decisions take place in a societal context in which disability is valued primarily in negative ways, and yet disabled people's everyday experiential knowledge of life with their particular disability is often at odds with this valuation (Parens and Asch, 2000; Shakespeare, 1999). Williams et al. (2002) for example, have argued that there has been a tendency within the medical profession, when offering advice to would-be parents facing screening and testing decisions, to focus on the medical complications associated with particular disabilities, rather than the (often) positive experiences of those currently living with the condition. Consequently, there have been calls for more 'balanced' information to be made available to would-be parents about the reality of life with disability (Shakespeare, 1999), and a cross-referencing of the literature around prenatal testing and experiences of disability within families (Kelly, 2009). For some writers, this extension of 'balanced information' has included a recommendation that prospective parents access experiential accounts of disability and impairment, whether through contact with

disabled people living with the condition to be tested for (Fletcher, 2002), or through web-based resources (Ahmed et al., 2007).

Whilst the political value and relevance of experiential knowledge is established in the disability rights literature, however, very little is known about the way in which it is used and represented in actual prenatal testing and screening decisions. There is some evidence to suggest that this knowledge informs screening and testing decisions (in various ways) both in the literature (Etchegary et al., 2008; Bryant et al., 2005; Chaplin et al., 2005; Gow, 2000; Chen and Shiffman, 2000) and anecdotally (Atkinson, 2008; Bowler, 2006; Lancaster, 2011), however there have been relatively few analyses focusing specifically on this form of knowledge. Two recent studies have explored the role of experiential knowledge of the condition being tested for in reproductive decisions (France et al., 2011; Etchegary et al., 2008), however the participants in these studies did not have a familial history of the condition (with the exception of four participants in France et al.'s (2011) study), and thus much of the experiential knowledge reported was of a more distant 'empathetic' nature and did not include an analysis of the influence of more intimate, or 'embodied' experiential knowledge (Abel and Browner, 1998).

This paper will address this gap in the literature, by highlighting the way in which experiential knowledge of an inheritable condition, Spinal Muscular Atrophy, is negotiated in reproductive decision making *within* families, including family members of varying levels of proximity to the experience of the condition, and thus with contrasting ways of 'knowing' SMA. The familial context of this analysis brings into sharp focus many of the key issues around the uses of experiential knowledge, including what counts as experiential knowledge (both embodied and empathetic), who is entitled to lay claim to it and how it is of use in the context of reproduction. In

order to consider these issues, an analysis of sixty-one qualitative interviews with families living with Spinal Muscular Atrophy will be presented and discussed. Firstly, the accounts of those whose experiential knowledge was mobilised to reinforce and confirm their reproductive decisions will be presented. Secondly, some of the ways that families found experiential knowledge to be a restrictive, rather than assistive, resource will be discussed.

Spinal Muscular Atrophy

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 both parents to carry one copy of the deleted SMN1 gene (believed to cause SMA) to transmit SMA to future generations. 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 degeneration of the anterior horn cells of the spinal cord leading to generalised, and often severe, muscle weakness. SMA has been sub-categorised into three distinct clinical ‘types’ (I-III) with different presentations, ages of onset, severity of muscle weakness and prognosis (ranging from early infantile death in the case of type I to late onset muscle weakness in adulthood in type III). However, in spite of these categorisations, the boundaries of the types of SMA are widely contested within the medical community and there indeed appears to be vast overlap in symptoms between them (Dubowitz, 1991, 2008). For example, infants with a clinical diagnosis of SMA type I have been known to survive well into childhood, and some children diagnosed as having type II SMA (an intermediate form of SMA, usually associated with an inability to walk from early childhood) go on to become ambulant for many years (Dubowitz, 1991, 2008). Whilst

the classifications of SMA, therefore, may give a guide to clinicians and families as to the likely trajectory of the disease, there remains a large degree of uncertainty as to how SMA will be experienced by an individual and the severity of the muscle weakness.

Spinal Muscular Atrophy and Reproductive Genetics

In order to understand the reproductive dilemmas faced by families living with SMA, it is necessary to understand the way in which SMA is inherited. It is estimated that one in forty people in the general population are 'carriers' of the deleted SMN1 gene thought to cause SMA, i.e. they can transmit the condition but have no symptoms themselves (Wirth, 2000). When such parents reproduce, they have a:

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

As population screening for SMA is not yet offered (although there are calls to introduce it (Prior, 2008; Su et al., 2011)) people usually learn they are carriers for SMA when their child or relative is diagnosed. Both prenatal testing and Pre-Implantation Genetic Diagnosis (PGD) are licensed for use in the UK for SMA, and relatives of a person diagnosed with SMA can also undergo carrier testing of themselves and their partners to assess their risks of transmitting the condition to offspring.

Whilst prenatal testing is available for SMA, however, the test cannot accurately predict the severity of SMA to be expected. The severity of SMA in existing relatives is often cited by geneticists and genetic counsellors as a rough

guide, although there are many cases of different ‘types’ being diagnosed within one family (Dubowitz, 1991). The wide spectrum of severities associated with SMA, therefore, and the inability of prenatal tests to discern them, adds complexity to the reproductive dilemmas faced by prospective parents with SMA in their family (Opera et al., 2008) and heightens the role of experiential knowledge in assisting reproductive decisions.

Methods

Interviews were conducted between 2007 and 2009 with sixty-one participants who all had at least one person diagnosed with SMA in their family (see Table 1 for the types of SMA diagnosed within the sample). Family members with differing levels of proximity to the diagnosed person (e.g. parent, sibling, grandparent) were included to allow an analysis of different forms of experiential knowledge (see Table 2). The interviews were designed to elicit participants’ stories of life with SMA before moving on to a discussion of views around, and uses of, reproductive technologies. The practical and ethical implications of completing this research are discussed elsewhere (Brown and Boardman, 2011).

Participants were recruited into the study through the main advocacy group for people living with SMA in the UK, the Jennifer Trust for Spinal Muscular Atrophy (JTSMA). The JTSMA currently supports around two thousand families living with SMA in the UK (JTSMA, 2011). Recruitment occurred through a variety of channels- through the JTSMA annual conference (n=16), through advertisements placed in JTSMA publications (n=16), personal contacts (n=3) and snowball sampling (n=22). Snowball sampling allowed for the inclusion of several members of the same family

which facilitated a direct comparison of different levels of experiential knowledge, which strengthened the analysis.

In order to allow for the possibility that people living with SMA might not identify with their diagnosis or with the values of the JTSMA, as well as to circumvent some of the class and gender biases associated with support groups (Stockdale and Terry, 2002) recruitment was also attempted outside the JTSMA, through disability organisations (Motability and DaDa) as well as personal websites set up and run by families living with SMA, however, these methods only led to the successful recruitment of four participants.

As the participants were geographically dispersed within the UK, interviewing also took place through a variety of channels: forty-four were carried out over the telephone, ten via email and five were face-to-face (four interviews were joint interviews and one participant was interviewed twice). Telephone and face-to-face interviews lasted on average for one hour and ten minutes, and the 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 via email (Burns, 2010). This method of interviewing allowed participants to answer in instalments, at times and dates of their convenience (McCord and Schwaber Kerson, 2006), which facilitated participation due to the (potentially) emotionally demanding nature of the topic and because the majority of participants were caring for young children/managing complex disabilities. Moreover, five of the ten participants who opted for this type of interview stated that it was in order to have time to carefully consider their responses. The method of interviewing employed was determined primarily by participant preference, but also took into account their geographical location, as well as the constraints of the research budget. The ethical

considerations associated with using these different interview techniques (particularly in the context of being a researcher with a visible disability), as well as the implications they had for the data produced, are discussed elsewhere (Brown and Boardman, 2011). All of the data presented in this paper are derived from telephone interviews.

The interviews were transcribed verbatim (with names and identifiers removed or changed), and the text responses from the email interviews were compiled into single documents for analysis. A constructivist approach to grounded theory data analysis was used- an approach that allows for an understanding that data is co-produced by both researchers and participants, and constructed through the interpretive lens of both the researcher and the researched. This approach was considered appropriate for an interpretive study of participants' perceptions of life with SMA as well as their genetic risk. Initially, 'open coding' (Gibbs, 2007) of the data was undertaken which was largely descriptive, before hierarchical coding was undertaken through the use of qualitative data analysis software, Nvivo 7. A process of coding, refinement of concepts (through data interpretation), followed by re-coding and further sampling were carried out over a period of eight months until 'theoretical saturation' (Glaser and Strauss, 1967) had occurred.

Findings

Experiential Knowledge as Assistive Resource

For families, experiences of living with SMA were often described as an important way through which future lives with SMA could be imagined, and reproductive decisions arrived at. Living intimately with SMA, and often also having close involvement in the lives of other families living with SMA, meant that some

participants in the study felt quite confident in their ability to predict not only what life would be like for a future child affected by SMA, but also their ability to manage it as a parent to that potential child.

Matthew is in his twenties and is the able bodied sibling of Cara, who was diagnosed with type II SMA in childhood. Matthew reported that his experiences of growing up alongside a sister with SMA, but also working with disabled people, shaped his perception of the concept of having a child with a disability more generally:

I think sort of having the family history I have, living with my sister for twenty-five years, makes me far less inclined to be worried about having a disabled child myself, whether it be SMA or Down's Syndrome or whatever because [pause] because I don't see...you know I went on to take a job with disabled people, I work with students who have Down's Syndrome and similar conditions, which I probably took on because I have that insight and I...I certainly see that it doesn't make them of any less worth...When you're close to disability, you start to see it as simply a different way of doing things, rather than a problem. It's just an example of difference within individuals [...] so no, I've never been interested in knowing what my carrier status [for SMA] is because it won't make a difference to me. I'd value any child the same.

Despite the fact that Press et al.'s (1998) and Etchegary et al.'s (2008) respective studies suggest that women's personal experiences of disability, whether within their own families or broader social circles, do not necessarily lead to more accepting attitudes about the possibility of having a disabled child themselves, for Matthew (as

for a further five of the seven able bodied siblings of people with SMA), living alongside SMA allayed any fears about having a disabled child himself. As Matthew reported, feelings about having a child with SMA were correlated with his feelings about disability more generally.

As well as those participants who stated that their experiential knowledge reassured them as to the potential quality of life of future lives affected by SMA, for other participants, their experiential knowledge of life with SMA left them equally certain in their perspective, but steered them towards entirely different reproductive decisions. For parents of children who experienced severe SMA and died in infancy, or those who experienced ongoing illnesses, the suffering associated with SMA was presented as an unquestionable fact.

Fraser is in his fifties and experienced the gradual deterioration and eventual deaths of his first two children as a result of type I SMA at ten and eight months of age respectively. He and his wife Charlie went on to have two able bodied children after prenatal testing for SMA was introduced in 1995, having terminated their first pregnancy after their children's deaths due to a positive prenatal test for SMA. The finding that parents of children with Type I SMA, like Fraser and Charlie, were more likely to go on to have further children than those of children with Type II or III reflects earlier studies of the reproductive decisions of couples following the birth of a child with a genetic condition. Indeed, D'Amico et al. (1992) found that those parents whose child died in infancy were far more likely to attempt further pregnancies than those parents whose affected child survived. Fraser's account of his reproductive decision making was less fraught with the uncertainties and dilemmas reported by other participants as the suffering his first two children went through left no room for interpretation and made him feel secure in the meaning he attributed to his

experiential knowledge-that it was a warning as to the poor quality of life associated with SMA:

...the ability to undergo prenatal testing was a Godsend to us because no one would want that if they could avoid it and I think everybody would say the same who is affected by it. I don't see any dilemma at all with type I testing, the test is there and every parent should take advantage of that [...] I know some people talk about type Is living past their first birthday, but that wasn't going to be the case for our children, so I think I'm sitting in the securest spot in the whole argument. No one could argue with my decision...because of the outcome with type Is.

The broadly different presentations associated with SMA and inability of the prenatal tests to distinguish between them means that there remains a large degree of uncertainty surrounding prenatal testing for SMA. For Fraser, however, like the parents in Roberts and Franklin's (2004) study, the suffering and shortened life expectancy that would be experienced by his future children was presented as a certainty; Fraser reported that he *knew* that survival wasn't going to be possible for any of his children with Type I. By representing his reproductive decisions in this way, Fraser was able to more easily conceptualise where his reproductive responsibilities lay: to prevent the suffering associated with SMA in future generations through the use of genetic technologies.

Whilst Matthew and Fraser were therefore quite clear in the way in which they interpreted and used their experiential knowledge in the representation of their reproductive decisions (even though these decisions were very different from each other), for other participants, rather than clarifying and strengthening their position,

experiential knowledge of the condition being tested for could introduce new levels of complexity to reproductive decision making.

The Limitations of Experiential Knowledge

Whilst experiential knowledge of SMA was treated by some participants as a taken-for-granted product of their experiences of the world, for others, it was described as a privileged form of insight available only to a minority of individuals. Participants in this study came to know SMA from a variety of different perspectives: as the parents, carers, spouses, siblings, partners, or children of individuals with SMA, or people diagnosed with SMA themselves. The question as to which of these individuals had access to the appropriate experiences, identities and subjectivities to give them a validated standpoint from which to lay claim to ‘knowing’ SMA (and thus able to predict its likely future impact), however, was contested within the families themselves. Indeed, despite the ‘empathetic’, as well as ‘embodied’ (through emotion and care work) (Abel and Browner, 1998) experiential knowledge of SMA possessed by the siblings of people diagnosed with SMA, such as Matthew, the accounts of some people diagnosed with SMA themselves suggested different criteria by which a person can ‘know’ SMA.

For many participants diagnosed with SMA, their family members’ knowledge of what it’s like to live with the condition was always partial and incomplete. Gill is in her fifties and was diagnosed with SMA type II in childhood. Whilst Gill’s able-bodied brother, Luke (also interviewed), reported having acquired a positive attitude to having a disabled child himself through his (largely) positive experiences of growing up alongside, and witnessing, his sister’s disability, Gill disqualified her brother’s knowledge claims when she talked about her life with SMA:

I definitely feel that no one can ever know what SMA is really like until they live with it themselves, you know, they've got it. Because other people, outsiders, no matter how close they are to you, they could be in your family even, they can't put themselves in your position. And my brother, he doesn't really know how much help I need, because while I was at home with him growing up I was quite capable of doing quite a bit for myself, it's only since I've moved out and lived on my own that now I need PAs [personal assistants] all the time...He [Luke] knows I need help, but I don't think he knows how much help I need. So it's really just between me and my PAs [personal assistants]. Not even my friends...it's not something you...talk about...[...].nobody sees that apart from the person who's helping me. And even then, how do they know how it feels to you? So yes ...you can't know unless you've lived that life.

Whilst Abel and Browner (1998) distinguished between 'embodied' and 'empathic' knowledge in the way in which people gain experiential knowledge, for Gill, experiential knowledge was a bounded form of knowledge; it could only be accessed by those living with the condition themselves, and was not transferrable to 'outsiders' by virtue of them living with her. There is a strong contrast between Luke, Gill's brother, who described his experiences with SMA as 'first-hand', and Gill who referred to all people as 'outsiders' - outside of her body, perspective and standpoint and thus ineligible to evaluate her life. Indeed, as her care needs changed over time, and she moved out of the parental home, her experiences of SMA began to change; she took on personal assistants and experienced independent living, and thus her brother's knowledge of what life with SMA was like became outdated, pointing to the

way in which experiential knowledge, even for the person diagnosed with SMA, can only ever be incomplete and partial, contained by past and present circumstances, and constantly subject to revision and change .

For Gill, being able to discredit Luke's perception of her life with SMA was particularly important in relation to her interpretation of his eventual decision to undergo carrier testing prior to him having his two children (in spite of his reported indifference to having a child with SMA). Indeed, for people diagnosed with SMA themselves, being able to claim authoritative knowledge of SMA could serve as a bastion against the emotional harm associated with the thought that Luke might wish to prevent a life affected by SMA. As Gill commented when recalling her brother's decision to undergo carrier testing:

I actually gave Luke all the information [about the genetics of SMA] before he and his wife started trying for a baby, so they could know about their options and choices and I was glad they had it, but once I'd given the information, I realised that information is really powerful and that then they had a choice and I started to think, if I had known that she [Luke's wife] was pregnant and she had a little baby with SMA, and they got rid of it, I mean that would have been shattering. Because that tells you a lot about what they think about my life. And actually my life, from where I'm seeing it, is probably a hell of a lot better than most people's...but they can't see it from where I'm seeing it, only from where they are, which is probably quite different, so their decision wouldn't really be based on reality, if you know what I mean.

Being able to police the boundaries of who could claim experiential knowledge was crucial, not just for individuals with SMA considering the reproductive decisions of others, but also prospective parents (with and without SMA), as it enabled participants to discredit the perspectives of others who may criticise their decisions or viewpoints (by labelling them as ‘ignorant’ or not suitably qualified to comment on life with SMA) or protect against the emotional harm inflicted by the reproductive decisions of others (Boardman, 2011).

This risk of emotional harm to family members was indeed a key concern of many participants living intimately with SMA- it complicated their reproductive decisions and closed down particular ways of justifying and presenting them. Claire (aged thirty-two) is the able bodied sibling of Leah, now in her twenties, who was diagnosed with type II SMA in childhood. Claire has a long term partner and was considering having children at the time of interview. However, Claire’s family experience with SMA left her in what she felt was an impossible dilemma:

Yeah I think I’m in quite a difficult position really because of what I know. Because my first thought was that I would never bother with any sort of testing [for SMA] if we were going down that route [having children] because I know SMA quite well really and I see what a wonderful person Leah is, and you know we often say that her condition has given her strength, mental strength, that she may never have developed otherwise...but I also know the other layers of it. I suppose it sounds sort of cold to say it, but it’s human nature to sort of think ‘if that could be preventable for somebody...Is it going to be really difficult or is it something that you can take on?’ Of course you’re going to

want the child that doesn't struggle with things...so on the one hand I've got that, but on the other hand I've got 'what would that say to Leah?' It would be like me saying that she wasn't important or that her life wasn't worthwhile with her condition. So where do you go with that? Um yeah I'm stuck between a rock and a hard place!

Claire's dilemma tallies with the reproductive dilemmas of parents of children with genetic conditions reported in Kelly's (2009) study. For such parents, removing themselves from the 'technologically imposed' reproductive decisions (Kelly, 2009: 84) was a strategy used to circumvent the dilemmas around becoming pregnant described by Claire, and also echoed in the accounts of many other parents and siblings of children with type II SMA. Unlike the parents of children type I SMA, who often presented their reproductive decisions in terms of the need to prevent 'certain' suffering with SMA, families living with type II had to negotiate their reproductive decisions around their experiential knowledge of life with a condition around which a successful and fulfilling life could be built. This tension between wishing to prevent disability in future offspring and yet also acknowledging the value and worth of a person's life with that particular condition is reflected in what Larson (1998) refers to as the 'paradox' of disability. Through her interviews with Mexican mothers of children with disabilities, Larson (1998) outlined the friction that existed in the mothers' lives- between their feelings of love for their disabled child, but their simultaneous desire to eradicate the disability and problems associated with it (Larson, 1998: 865). Indeed, this difficulty with separating out the child (or potential child) from the disability is at the heart of much of the disability rights response to prenatal testing and selective termination (Asch, 1999; Edwards, 2004). Whilst, as

Edwards (2004) has argued, the ‘expressivist objection’, or the notion that prenatal testing and selective termination expresses a negative valuation of people living with the condition being tested for, rests on a false notion that disability is wholly identity-constituting, what is clear that it is nevertheless an important influence on the way in which families affected by genetic conditions approach reproductive decision making. For Claire, a decision to prevent the birth of a child with SMA could not be justified or substantiated through the notion of protecting the ‘best interests’ of the future child, indeed, her experiential knowledge of her sister’s life suggested that a diagnosis of SMA was not incompatible with a good quality of life; thus Claire became trapped between her experiential knowledge and her own fears about what her own child’s life would be like with SMA.

Discussion

Through interviews with families and individuals affected by SMA, experiential knowledge of the condition being tested for emerged as a key mediator in the decision making processes around the use of genetic technologies and selective termination, as has been demonstrated elsewhere in relation to families living with other genetic conditions (Kay and Kingston, 2002; Kelly, 2009; Beeson and Globus, 1985), and in decision making surrounding antenatal screening (France et al., 2011; Etchegary et al., 2008). Participants in this study approached reproductive decision making in the context of having lived with someone with SMA or having SMA themselves, through which they assessed their genetic risk, formulated their reproductive decisions and accounted for these decisions. For many participants, presenting SMA as a disability that could be ‘overcome’ and around which a happy and fulfilling life could be

established, was justified by reference to intimate experiential knowledge of SMA. For these participants, experiencing SMA in their family was described as an important influence on attitudes to disability more generally; allowing them to see disability in a positive way having witnessed their family cope successfully with SMA. For disability rights supporters, such experiential knowledge of disability is crucial in balancing out the medicalised portrayals of the conditions which are often presented in the context of antenatal screening consultations (Fletcher, 2002; Asch, 2000).

It is noteworthy, however, that experiential knowledge of SMA was also strategically mobilised in a similar way by participants who took measures to prevent the lives of future people with SMA. By drawing on the suffering of previous or existing family members with SMA, participants were able to justify their decisions to take active steps prevent further lives affected by the condition. Consequently, this analysis highlights that the way in which experiential knowledge is used in reproductive decision making reveals more about the way that it is valued than what is actually decided; similar strategies of prioritising and valuing experiential knowledge of SMA (as an indicator of future suffering), were used both by those who wished to prevent, but also those who felt comfortable with, the possibility of SMA in their offspring.

This research, however, also outlines the possibilities for contestation around ownership of such experiential knowledge within family relationships, particularly around family members' right to claim 'embodied' or 'empathetic' experiential knowledge, as well as the status of these respective forms of knowledge (Abel and Browner, 1998). Whilst previous research has highlighted the way in which experiential knowledge may be defined according to its proximity to the experience in

question (Etchegary et al., 2008), previous analyses have overlooked the way the concepts of closeness and distance become ordered hierarchically in accounts of reproductive decision making. This study has demonstrated that participants developed a 'hierarchy of experiential knowledge' as an important means by which to check the authenticity of each other's accounts of life with SMA and to discredit (or justify) particular standpoints (Boardman, 2010). Those closest to the experience of SMA- those diagnosed with it- often laid claim to being at the top of this hierarchy of knowledge, achieved through their embodied experiential knowledge of SMA, over and above those family members who came to know SMA empathetically, through the experiences of their relative. D'Agincourt-Canning (2003)'s study of familial experiences of cancer, however, suggests that 'empathetic' and 'embodied' forms of knowledge can in fact become heavily intertwined in daily life; care work, for example, is a thoroughly embodied activity (D'Agincourt-Canning, 2003: 151), and family members living alongside SMA indeed described the physical and emotional impact of the condition in terms of their own embodied experiences. Whilst it may not be possible, therefore, to distinguish which accounts of SMA are more 'real' or offer 'better' insight into life with SMA, there was, nevertheless, certainly evidence that the hierarchical organisation of different ways of knowing SMA was an important strategy used in the justification of certain standpoints and decisions about reproduction, as well as the discrediting of others. Being able to claim 'closeness' to SMA and thus the ability to assign oneself the status of the 'knower', was an important way for the participants in this study to establish authority on 'their' condition and bolster the legitimacy, and validity, of their views and decisions around reproduction. The existence of such a hierarchy within participants' responses highlights some of the potential difficulties associated with imparting experiential

knowledge to the general public in the context of genetic screening programmes and the potential for contestation around its ownership and transferability between individuals.

By highlighting the various ways in which experiential knowledge is used and presented by families living with SMA approaching reproduction, this research has implications for professional counselling of families living with genetic disease. In particular, the findings suggest that it may be useful for genetic counsellors to explore experiential knowledge when counselling families affected by inheritable conditions, including the experiences and attitudes of those diagnosed with the condition, the experiences of caregivers and the impact these differing experiences have on perceptions of the condition and the conceptualisations of genetic risk. Such an exploration, as highlighted by Etchegary et al. (2008), may help counsellors to identify those individuals most likely to experience distress in prenatal or carrier testing counselling processes and who might benefit from additional support (p.123). This research, however, also points to some of the difficulties associated with making this form of knowledge available to prospective parents particularly for variable conditions or where multiple conditions are being screened for. including its potential to constrain reproductive decisions. Kaplan (1999) has argued that altruism is often used as a justification for selective termination decisions following the diagnosis of a disability or impairment. For individuals who participated in this study whose experiences with SMA were largely positive, the notion that prenatal testing and selective termination prevents future suffering could not be reconciled with their everyday experiences of life with SMA. Similarly, the issue of who is entitled to lay claim to experiential knowledge, even within families, could be sight of contestation and tension. For would-be parents then, experiential knowledge could at once provide

insight, but also, paradoxically be experienced as oppressive, increasing uncertainties around reproduction and rendering them trapped between competing concerns and demands. This research therefore points to some of the difficulties, as well as the benefits, associated with the advancement of experiential knowledge as a resource in reproductive decision making, particularly as a way to ‘give voice’ (Bricher, 1999) to the perspectives of those with disabilities in the prenatal testing and genetic screening debate.

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Tables 1 and 2
Knowledge is Power? The Role of Experiential Knowledge in Genetically ‘Risky’
Reproductive Decisions

Table 1: The Diagnoses of Spinal Muscular Atrophy within the Sample

Diagnosis	Number of Participants with Diagnosis in their Family	Gender	
		Female	Male
Spinal Muscular Atrophy Type I	12	11	1
Spinal Muscular Atrophy Type II	32	25	7
Spinal Muscular Atrophy Type III	11	10	1
Spinal Muscular Atrophy with Respiratory Distress*	3	2	1
Spinal Bulbar Muscular Atrophy*	2	1	1
Autosomal Dominant Spinal Muscular Atrophy*	1	0	1
Total	61	49	12

(* Variant Form of Spinal Muscular Atrophy)

Table 2: The Participants’ Relationship to the Person Diagnosed with Spinal Muscular Atrophy

Nature of Experience with SMA	Participant Numbers	Gender	
		Female	Male
Diagnosed with SMA Themselves	25	21	4
Sibling of person with SMA, without SMA themselves	7	4	3
Parent of person diagnosed with SMA	24	21	3
Grandparent of person diagnosed with SMA	1	1	0
Son or daughter of person diagnosed with SMA	2	1	1
Partner or spouse of person diagnosed with SMA	2	1	1
Total	61	49	12