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# Life 'on high alert': how do people with a family history of motor neurone disease make sense of genetic risk? insights from an online forum

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It is estimated that up to ten per cent of people with motor neurone disease (MND) have an inherited form of the disease. Families with a history of inherited MND may face specific issues around managing the condition in relatives and adapting to life knowing that they too could develop the disease, which we refer to as living 'at risk'. This qualitative study is based on a thematic analysis of posts from 37 threads shared on the MND Association Forum between 2010 and 2019. Through this analysis we explore how forum users make sense of, and negotiate, genetic risk in this online space. We unpack how risk is constructed through a tracing and reframing of family history in relation to MND; we draw out the different ways uncertainty is expressed by people living with the threat of the disease; and we outline how future decisions around genetic testing and reproductive choices play out on the forum. Genetic risk was articulated temporally, with posters reflecting on past, present and expected future experiences across posts. This was crosscut by profound uncertainty. How people understood and expressed experiences of living 'at risk' – and the responses they received from others – were grounded in different forms of experiential knowledge, intertwined with biomedical and genetic information. We propose the MND Association forum as an interactional site where uncertainties are negotiated and risk is made sense of by individuals with a family history of MND, alongside those affected by 'sporadic' forms of the disease.

**Keywords:** genetic risk; uncertainty; motor neurone disease; online forums; experiential knowledge

## Introduction

This article is based on our thematic analysis of posts on the MND Association Forum, an online forum used by people affected by motor neurone disease (MND), including inherited MND. We aim to explore how people with a family history of inherited MND make sense of and navigate decisions around genetic risk. In particular, we look at how risk is constructed through a reframing of family history in relation to MND; we draw out the different ways uncertainty is expressed by people living under the threat of the disease; and we explore how future decisions around genetic testing and starting a family

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are negotiated in this space. We focus on how experiential and biomedical knowledge become intertwined in this process, paying particular attention to the temporal experiences of living at risk as articulated on the forum.

In our analysis, we approach the online forum as an interactional site where uncertainties are negotiated between individuals with a family history of MND and other users, often affected by 'sporadic' forms of the disease. We suggest that this site not only provides a space where people share experiences but that, through acts of sharing and receiving information with others affected by the disease, it may also play a role in how people come to understand and make sense of genetic risk.

## Motor neurone disease and risk

### *Motor neurone disease*

MND refers to a group of adult-onset, neurodegenerative conditions, causing progressive muscle weakness and impeding the ability to walk, talk, eat, drink and eventually, to breathe. It is referred to as amyotrophic lateral sclerosis (ALS) in the USA and elsewhere. There is no cure, and survival from diagnosis varies, but more than half of those diagnosed die within two years. Up to 10% of individuals with MND have an inherited form of the disease, which in around 70% of cases can be linked to an identified genetic variant (Motor Neurone Disease Association, 2019). It is worth noting that the picture of MND as either 'sporadic' or 'genetic' is complicated by evolving research which continues to unpick the complexity of MND genetics (Shatunov & Al-Chalabi, 2021). Nonetheless, for the purposes of our study, we use this language to refer to cases where there is a family history of MND indicative of a hereditary form or where this has been determined through genetic testing. We use the term 'inherited MND', though 'familial' MND was used as a synonym by some forum users quoted.

Pre-symptomatic genetic testing is available for people at risk for whom one of the four most common known genetic variants has been identified in their family. However, even where genetic testing has identified an MND-causing genetic variant, it is not possible to say with certainty whether the disease will actually develop, predict when this might happen, or how symptoms will onset or progress. The proportion of individuals with a genetic variant who exhibit symptoms of the disease is known as 'penetrance'. Inherited forms of MND are therefore set apart from other genetic conditions like Huntington's disease by their incomplete penetrance, meaning that not everyone who has inherited a disease-causing genetic variant will necessarily develop symptoms. This continued uncertainty further complicates decisions about genetic testing.

In certain countries, including the UK, various reproductive options are available for people affected by inherited MND. Some individuals with a known genetic variant in the family can have pre-implantation genetic diagnosis (PGD), which uses IVF to screen embryos, implanting those without the identified genetic variant (Motor Neurone Disease Association, 2019). Whilst scientific advances in this rapidly developing field have led to clinical trials targeting particular genetic variants and renewed hopes for a treatment or cure, inherited forms of MND continue to be characterised by a complex genetic landscape, and multiple uncertainties remain.

***Families, genetics and risk***

The risks faced by people from families affected by inherited conditions can be thought of as distinctively corporeal or 'embodied' (Kavanagh & Broom, 1998), located inside the individual, with important consequences for understandings of the self and lived experiences of embodiment. The experience of living with embodied risk has been conceptualised as existing in an in-between state, a liminal or ambiguous space between health and illness (Kavanagh & Broom, 1998). In the context of inherited conditions, 'patients-in-waiting' (Timmermans & Buchbinder, 2010), 'pre-symptomatic persons' (Konrad, 2003) or 'perpetual patients' (Finkler, 2010) may be created by developments in genetic knowledge and technologies. In this context, 'illness experience and medical diagnosis have been severed and people experience illness in spite of symptoms or a diagnosis' (Timmermans & Buchbinder, 2010, p. 417). As such, corporeal risk can be perceived not just as a future threat but as a form of current illness (Kavanagh & Broom, 1998), including in genetic conditions characterised by incomplete penetrance. Research on women with BRCA 1 and 2 mutations, for instance, has shown that risk based on family history can be perceived as a diagnosis that requires a corresponding medical treatment (Frank, 2012).

In inherited conditions, knowledge around the disease and understandings of risk may be framed by personal experience. Initially coined as 'truth learned from personal experience' (Borkman, 1976, p. 446), the concept of experiential knowledge has been developed in relation to a range of conditions. Notably, it has been taken up to explore how personal experience provides a framework for understanding (genetic) disease, and as a basis upon which people visualise and make decisions on the future (Boardman, 2014; 2017). The concept has been expanded to distinguish between embodied and empathetic knowledge (Abel & Browner, 1998, p. 315), or knowledge derived from 'direct sensory experience', and that which is constructed through 'close emotional ties between individuals'. We make use of these concepts to explore different ways of knowing for people affected by MND, and how these feed into how forum users understand and talk about genetic risk. It is worth mentioning, however, that experiential knowledge cannot be positioned as opposing 'scientific' or 'professional' knowledge or as more or less 'correct' or 'incorrect'; rather the two are intertwined and co-constituted, yet also existing in tension (Abel & Browner, 1998).

Whilst the diverse implications of living with an inherited condition have been explored in a growing body of literature, the transformative effect of the new genetics has elsewhere been criticised as 'overstated' (Featherstone et al., 2006). In most hereditary illnesses, there remains much uncertainty around whether symptoms will develop, even in the case of a positive pre-symptomatic genetic testing result. Research has highlighted how counselling families around uncertainty is a major challenge for genetic counsellors (Arribas-Ayllon & Sarangi, 2014).

In this paper, we focus on the experiences of people affected by inherited forms of MND. The small existing literature on experiences of inherited MND (or familial ALS as it is referred to) suggests that living with genetic risk may lead to considerable anxiety, have a diverse impact upon people's lives and perspectives on the future, and play out in complex ways in decisions around pre-symptomatic genetic testing and reproductive choices (Fanos et al., 2004; 2011; Hartzfeld et al., 2015). Inherited MND offers a unique lens through which to explore experiences of genetic risk and uncertainty. It is set apart from other neurodegenerative, adult-onset, inherited conditions like Huntington's disease by its incomplete penetrance, yet is also distinct from other such conditions, like

hereditary breast and ovarian cancer, by its uncertain, diverse, and rapidly degenerating symptoms, lack of preventative options, long-term treatment or cure. The characteristics of particular conditions may play into the choices that are made around pre-symptomatic testing and acting upon risk (Chadwick, 1999), pointing to a need for further research around inherited MND.

### *Navigating illness on online forums*

Online forum data present an alternative to researcher-led methods and retrospective accounts (Coulson et al., 2007), providing a naturalistic account of how people respond to challenges in their lives and navigate complex decisions (Kenen et al., 2007). Due in part to their (perceived) anonymity, online forums may aid the discussion of sensitive subjects (Frank, 2012; Smedley & Coulson, 2019). They may be particularly relevant for people with MND, who may be geographically distant from others with the condition, and who face increasing difficulties with communication and mobility.

Researchers have explored forum use by people with a range of health conditions. These online spaces have been identified as sites for social support and connectivity, where people can interact with others in a similar situation to themselves, who understand what they are going through (Kingod et al., 2017; Smedley & Coulson, 2019). Forums provide a place where people can find emotional support, share their fears and distress, and find ways to cope (Coulson et al., 2007; Kazmer et al., 2014; Kenen et al., 2007; Radin, 2006). As such, these spaces have been characterised as a form of 'community' (Hargreaves et al., 2018; Kenen et al., 2007), where a deep sense of trust can develop, joining people in a 'virtuous circle of caring' (Radin, 2006, p. 599).

Acting as an information repository (Kazmer et al., 2014), the value of forums in providing informational support has also been emphasised (Frank, 2012; Kenen et al., 2007; Novas & Rose, 2000). As pragmatic spaces for seeking help (Hargreaves et al., 2018), forums facilitate the sharing of resources and strategies around a variety of issues (Locock & Brown, 2010; Radin, 2006), including personalised advice and guidance (Hargreaves et al., 2018; Smedley & Coulson, 2019). Crucial here is the sharing of experiential knowledge, through the exchange of rich, embodied and situated accounts grounded in personal experiences (Kingod et al., 2017). In the forum space, personal experiences interact with other sources of information to construct 'authoritative knowledge' (Kazmer et al., 2014), fostering a collective intelligence (Kenen et al., 2007), or 'groupthink' (Saukko, 2009).

Research on the use of forums around hereditary conditions has been carried out amongst those affected by Huntington's disease (Coulson et al., 2007; Novas & Rose, 2000; Smedley & Coulson, 2019) and hereditary breast and ovarian cancer (HBOC) (Frank, 2012; Kenen et al., 2007). This literature highlights forums as sites where people constitute themselves, and are constituted by others, as 'at risk'. Discussions around risk and inheritance are part of how people learn to narrate, reflect upon and manage their genetic identities (Frank, 2012; Novas & Rose, 2000). Invoking findings from Kingod et al. (2017), this highlights the potential of online forums for 'identity work', where people facing illness renegotiate their sense of self through the reciprocal sharing of advice, information and support. In this sense, forums offer a space for managing one's genetic status and the uncertainty that comes with this in interactions with others who understand (Kenen et al., 2007; Novas & Rose, 2000; Smedley & Coulson, 2019). People

also use forums in mitigating and responding to risk. Sharing and navigating multiple sources of knowledge and information, forum users make decisions around issues including pre-symptomatic genetic testing or (in the case of HBOC) prophylactic surgery, and gain confidence in their chosen course of action (Frank, 2012; Kenen et al., 2007; Smedley & Coulson, 2019).

Our study explores how people with a family history of inherited MND make sense of and navigate decisions around genetic risk in a specific online forum. We seek to contribute to research on the use of online spaces amongst people affected by different health conditions, and to a growing social scientific literature on living at risk of inherited conditions.

## Methods

The MND Association is the principal organisation providing support and information to people affected by MND in England, Wales and Northern Ireland. The MND Association Forum was selected for this research on the basis that it is popular, inclusive and freely accessible, with a member base predominantly from UK (Motor Neurone Disease Association Forum, 2019). No additional forum or social media sites were used due to the rich data available on this site. The study was approved by The Life Sciences and Medicine Ethics Review Board (CERB) at the University of Aberdeen, and the use of forum data for this study was granted by the MND Association.

This study focuses on posts around experiences of inherited MND, defined broadly as discussions which mention a family history of the disease and raise issues associated with genetic risk or living with an inherited form of MND. In order to identify posts related to inherited MND, a key word search was carried out on the forum. Key words included 'inherited', 'familial', 'gene' and 'genetic', as well as common genetic variants associated with inherited MND such as 'C9orf72′ and 'SOD1′. Other potentially relevant genetic variants, such as 'FUS', and terms like 'IVF' were excluded as the forum search function limits searchable words to those with a minimum of 4 letters.

All threads posted between the inception of the forum in 2010, and April 2019 when this search was carried out, were screened for relevance. Thirty-seven threads were included in this analysis, containing 332 posts from 68 users. Although they were not included directly in the analysis, the posts of other users have informed insights into and understandings around forum interactions. Threads ranged from 1 to 28 posts, with the most common number of posts being 7. The most common number of responses from original posters was 1 or 0, although at times other forum users commented on or reinforced each other's responses, lending to a conversational structure in some threads.

Forum threads were extracted from the MND Association website into NVivo using NCapture. Threads were coded thematically, through an inductive process whereby posts were read and re-read, and a preliminary set of codes drawn up. This framework was developed and revised over the coding process as new posts were read, and previous threads re-coded. Codes were also developed around forum dynamics to allow for consideration of the interactive aspects of forum communication.

Where quotations have been used, contextual information has been given, including a poster identification number (to highlight where posts have been made by the same individual), sex, whether or not there is a family history of MND, and whether the quote is the initial post in the thread or a response. In some cases, this information was not available on the forum. Whilst initial posts of the included threads tended to be authored

by those affected by inherited forms of MND, who were often new to the forum, many who responded were frequent users of the forum, and did not appear to have a family history of the disease. Quotations have been displayed as they appear on the forum.

'Internet-based technologies change the research scenario' (Markham, 2005, p. 247). As such, the need to reflexively interrogate our roles, methods, ethical stances, and interpretations is intensified as we move away from ways of doing things grounded in physical traditions (Markham, 2005). Online research therefore raises unique and complex ethical concerns, requiring a rethinking of concepts including informed consent and anonymity. In particular, the ethical requirement of gaining informed consent when conducting research using publicly available material, whilst not required legally, remains fraught with uncertainty (British Sociological Association, 2016). In this study we used publicly available material, with permission from the MND Association, meaning that we were not required to seek informed consent from contributors, a task that would have been impossible for practical reasons such as sporadic and discontinued use of the forum. Further, in joining the forum, users permit the MND Association to use any contributions for future purposes (Motor Neurone Disease Association Forum, 2019). Nonetheless, we acknowledge the ethical tensions that remain, as it was unlikely that users expected their posts would be used for research and did not write with this audience in mind. In partial response to this, potentially identifying information has been omitted from quotations used. Additionally, we had carried out searches on the forum to assess the retrievability of quotes used. Whilst we are satisfied that quotes are not easily retrievable, guaranteeing complete anonymity is not possible due to the public nature of the forum.

## Findings

We present our data thematically for analytic purposes, although themes were intertwined in narratives. Individuals appeared to use the MND Association forum for many reasons, from simply sharing their experiences and telling their stories, to seeking others in a similar situation to themselves, to searching for specific advice and information.

### *'It raised a lot of questions': navigating family histories*

Initial posts often started with forum users tracing MND through relatives, at times over generations. Such family histories set the context for the sharing of hopes and fears, concerns and dilemmas. Individuals reconstructed the past to make sense of their current situation, with some attempting to determine their future risk in relation to an ambiguous family history. This form of 'biographical narration' has been described as a way people construct themselves – and are constructed by others – as 'at risk' (Novas & Rose, 2000). The example below highlights how questions over family history interact with scientific and biomedical knowledge:

> My mum has been recently diagnosed with MND. We have learnt that my Great Grandfather died from Muscular atrophy in the 1940's, which I understand falls under the MND diagnosis. Obviously it has all come as a major shock to us all but it raised a lot of questions about familial MND. For it to have been passed to my mother it would of had to have come through my Grandmother? She lived to 94 and died of a stroke. Her two brothers also lived into their 90's. As of yet, none of my mothers siblings, in there 60's & 70's have developed it, or any of my older cousins. My understanding has been that it doesn't skip generations and a lot of literature suggests that FALS will appear within each generation. I'm trying to

> get an understanding of whether myself and my brother are at risk … *(Poster 26, potentially at risk/ family history uncertain, original post).*

Responses to these kinds of posts varied, with users drawing from a variety of experiences and knowledge to reassure others and attempt to untangle these complicated and uncertain family histories. Some evaluated the details given to interpret the information and assess whether it could point to an inherited form of MND. In the post below, the uncertainty and complexity of scientific research around inherited MND are reflected in the (mis)understanding expressed by this forum user. This response, to a woman concerned about her risk due to an uncertain family history, highlights how such reassurance may be unintentionally misleading:

> … the odds against are fantastic. The odds of getting the disease are in the region of 100,000 to 1. The number with Familial disease are 5% therefore the odds of developing the illness genetically only 1 in 20 therefore 2,000,000 to one. Beyond this there are twice as many men as women get the illness so your chances are negligible in real terms. *(Poster 10, M, partner of person with MND (now deceased)/ family history unknown, response).*

In other discussions, forum users acknowledged the increased risk of those with a family history of the disease, though as above, some emphasised the perceived rareness of inherited forms.

### *A game of odds: winners and losers in the genetic lottery*

Forum users indicated an awareness that the most common identified genetic variants responsible for inherited forms of MND follow an autosomal dominant inheritance pattern. Although this terminology was not used, people often mentioned that the chance of inheriting the disease-causing genetic variant where a parent has been affected by an inherited form of MND is 50%. Individuals often discussed their risk in terms of this statistic, framing their future as a matter of chance. One forum user spoke of her anxiety for her future, but also held deep fears for other family members:

> I really hope dont inherhit this awful MND but then I also hope my brother dose not either. But knowing that there is a 50% chance that one of us will it brings me to tears … its hard for it not to let it take over your mind. But the odds are high. if I do not suffer with it then I suffer to see it eat away someone i love for the 3rd time. *(Poster 1, F, at risk/ known family history, response to own original post).*

Forum users, both with and without a family history of MND, held different amounts of knowledge of the penetrance of genetic variants associated with MND. Whilst some did not distinguish the 50% risk of inheriting the gene from the chance of developing symptoms, others were aware that not everyone with an MND-causing genetic variant will necessarily develop symptoms. As one forum user described, developing the disease is ‘a lottery’. The likelihood of winning or losing, however, was unclear; forum users had been told different statistics about the likelihood that MND would manifest in people at risk, with individuals presenting a range of contrasting statistics on the site. This reflects an incomplete and shifting scientific landscape, where the penetrance of MND-causing genetic variants is similarly hard to quantify.

### *'Sitting on a time bomb': MND as an inevitable future*

MND was expressed as an ever-present fear in the lives of some people with a family history of the disease. Many people described being scared and concerned for the future of themselves or family members, often following the diagnosis or death of relatives. Although some framed their risk as a matter of chance, finding hope in uncertainty, others took a more fatalistic view, seeing MND as inevitable.

The constant threat of MND is highlighted in its characterisation as a 'time bomb'. Partners of people with MND in particular expressed fears for their children and other members of the family, and a sense of waiting for the disease to take hold:

> My husband, his mum and an uncle all died of familial MND and now it is just like sitting on a time bomb waiting to see if our children, nieces, nephews etc. get it … reading this forum scares me because there are so many younger people with it. *(Poster 6, F, partner of person with MND (now deceased)/ known family history, response).*

> It is also a genetic form of MND - this is becoming a real struggle for me. I feel like we're just waiting for my partner to get MND. *(Poster 2, F, partner of person at risk/ known family history, original post).*

Another individual, who had lost several family members to MND, spoke of the disease as inevitable. Imagining her future as reflecting that of affected relatives before her, she positioned MND not as a matter of 'if' but 'when':

> My Mother died in 1968 and have since found out that it is hereditary in my family. My Grandmother, uncles, aunt, brother and late Nov my Sister. i am heartbroken. It makes my mind wonder when my time will come and that i will not have my kids and grandkids visit because i remember seeing my Mum in hospital. i also watched my Brother die and that nearly killed me too. (Poster 9, F, at risk/ known family history, original post).

Fears around genetic risk were met with a range of responses, from those both with and without a family history of MND. Forum users offered support and validated the difficulty of inherited forms of the disease. They shared information on the inheritance of MND, often highlighting the dual chances of non-inheritance or incomplete penetrance. People promoted attitudes and advice on living with these uncertainties; staying positive, making the most of life, and not worrying about something that may never happen were emphasised.

### *Living 'on high alert': when risk takes on a heightened significance*

People often posted on the forum at 'critical junctures' (Cox & McKellin, 1999), such as the diagnosis or death of a family member, and around decisions over starting a family. In families with an apparent pattern in the age symptoms develop, younger generations seemed to develop a heightened awareness of MND as this time approached. This is reflected in the post of one individual who had received a negative pre-symptomatic genetic testing result himself but who had a sibling and cousins at risk, highlighting genetic risk as a distinctly familial matter:

> I now have cousins who are reaching the age where our family seem to start showing symptoms, so we are pretty much on high alert. I think that there are 19 of us in our generation of which 9 have a parent who has had MND. They say statistically for familial, it

> is around 50% hopefully it's not the case but for my dad's generation it has been pretty much that figure. *(Poster 15, M, no longer at risk/ tested negative, response to own original post).*

Where there is a family history of MND, bodily sensations that might be brushed off or dismissed in daily life can take on a particular significance. Several people at risk, yet to receive a formal diagnosis, used the forum to describe their symptoms, in some cases asking if other users had experienced anything similar. Whilst some expressed uncertainty over whether their symptoms were due to MND, others believed strongly that the disease would be confirmed. Responses to such concerns acknowledged and validated these fears, yet there remained a strong wish to encourage hope, and re-construct the threat of MND as a risk, not an inevitability. Respondents also pointed out that the described symptoms may not be due to MND, especially when these details did not align with their knowledge or experience of the disease.

Knowledge of a family history of MND led to some individuals watching themselves and others with increased vigilance. One forum user who had received a positive pre-symptomatic genetic testing result used the forum to seek information from others on early symptoms she should be aware of. Posters also referred to monitoring the bodies of relatives at risk. Another individual, whose partner had developed MND, spoke of a perpetual terror that other family members would develop symptoms. Knowledge she had gained from people on the forum on supposed risk factors of the disease (such as finger length ratio, the significance of which has been explored in research by Vivekananda et al. (2011)) fed into such fears and served as a basis upon which to inspect younger generations of her family:

> I do read the forum nearly every day as his was the familial form and I live in terror of my children and grandchildren developing this, I am constantly looking for signs such as the length of fingers recently mentioned on here. *(Poster 6, F, partner of person with MND (now deceased)/ known family history, response).*

Information gained from the forum can shape people's experiences and anxieties around risk in both positive and negative ways. One woman became aware from reading forum posts that younger people can develop the disease, which she previously had associated with older age, making the perceived risk to her children more immediate.

### *'I am in two minds': the dilemma of pre-symptomatic genetic testing*

Across the forum, pre-symptomatic genetic testing was a prominent topic of conversation, often arising in conjunction with discussions on starting a family. Whilst some simply wanted information on accessing genetic testing, others had already made this decision. Forum users included those who had decided not to take the test, as well as people at various stages in the process. Decision-making around pre-symptomatic genetic testing was a juncture around which many posted on the forum, sharing their dilemmas with other users, some of whom had first-hand experience of making the decision themselves, and all of whom had experienced MND in some capacity. Often, the decision over pursuing pre-symptomatic genetic testing was fraught with competing arguments.

People at risk acknowledged pre-symptomatic genetic testing as a complex decision, laying out both hopes and concerns on the implications it could have across aspects of their lives. Concerns included the impact of a positive result on financial opportunities, such as securing a mortgage, and the anxiety and upset that could result. Hopes included

receiving a negative result. The benefits of the test were often framed in terms of aiding reproductive choices and preventing future children from inheriting the disease-causing genetic variant. Although it was suggested that the test could give peace of mind, responses from other forum users, generally without a family history of the disease, were often against pre-symptomatic testing.

Many forum users urged caution around pre-symptomatic genetic testing, arguing that in the absence of a treatment to prevent onset or progression of the disease, knowing one's genetic status offers no clinical benefit. Posts raised the possibilities of non-inheritance and incomplete penetrance, uncertainties which were drawn upon in instilling hope; a positive result was seen to cause excessive anxiety about something that may never happen. Respondents were also hopeful for a cure and advised the younger people at risk that therapies could materialise by the time they were likely to be affected. In such discussions, living life to the full, remaining positive, and enjoying every day were emphasised. Although many of these individuals did not appear to have a family history of MND themselves, they drew on experiences of other illnesses and events within their families, from cancer to accidents. A response to a young woman who was unsure over whether to pursue pre-symptomatic genetic testing in the context of an uncertain family history exemplifies some of these ideas:

> . . . I totally get your fears because I also experienced that at your age and beyond. Only not with mnd, but with cancer . . . Can only suggest to you from experience is to just get on with living your life now in this moment, for today with joy and happiness . . . I can't see how having the knowledge of having the gene or not would be beneficial? It will only have you spending your life worrying on the if and when you will develop it, in which case you may never, and even if you do you could be in your 70's . . . by that time you will take a pill and it will be gone! Or you will be injected with some healthy stem cells and your body will recover! That day will be here soon, so hope you can do your very best to stop worrying over it. *(Poster 22, F, friend of* person *with MND/ no known family history, response).*

### *'If it was just me involved . . . i wouldn't want to know': starting a family in the context of genetic risk*

Dilemmas around having children were intimately tied to decisions over pre-symptomatic genetic testing, which was perceived as a basis for making reproductive decisions; the availability of genetic technologies introduces a new sense of responsibility to act upon risk (Novas & Rose, 2000). Forum users expressed a desire to prevent future children from being at risk, but how testing information would be acted upon was unclear. One forum user described a conflict between her personal wishes of not wanting to know her genetic status, and her sense of responsibility towards future children, which arose in a context where genetic and reproductive technologies were available:

> I suppose really if it was just me it involved or if I'd already had children I wouldn't want to know but it's niggling at me that I could have the opportunity to find out and maybe save a child from having it. *(Poster 5, F, at risk/ known family history, response to own original post).*

A sense of responsibility to future children also arose in other posts, with one forum user with an uncertain family history sharing his decision to hold off having children in the hope that scientific developments would lead to a treatment in the coming years.

Decisions around having children were further complicated for individuals where other factors came into play. For one woman, whose mother and brother had MND, genetic testing had failed to identify an MND-causing genetic variant. This uncertainty meant that she could not seek pre-symptomatic testing and had limited options when making decisions around starting a family. Further factors and restraints introduced additional considerations, highlighting that reproductive decisions must be made in the context of genetic uncertainty, wider institutional structures and familial responsibilities:

> I am at a bit of a loss at what to do … I dearly want children and as I am nearing 40, dont have much time to wait around. [Consultant] said perhaps I could have some eggs frozen and if they find a gene later on that is responsible for our familys illness, they could test my frozen eggs for the faulty gene and extract it. Then to have the healthy eggs implanted using ivf. But I have recently found out ivf is only available to women on the nhs up to the age of 40. My dilemma is do I go ahead with this, try and have children naturally and wonder if I have passed on a faulty gene to them or not have children? Another big problem is time, I am so busy being a full time carer. How can I even think of my future, which I need to start planning now, when my mum is filling up all my time? *(Poster 33, F, at risk/ known family history, response). response).*

Although some respondents to these forum posts validated the complexity of these decisions and acknowledged that they would want to know their genetic status if they were young enough to have children, most promoted a pro-natalist position, echoing arguments against genetic testing. People highlighted the late onset of the disease, and the possibility of having a long life before MND develops. A response to one post contrasted having a child at risk of MND with the chance of passing on childhood diseases, which was deemed to cross a moral line towards the unacceptable. Respondents without a family history of MND themselves invoked uncontrollable events to highlight the unpredictability of life, and experiences of infertility were drawn upon as a basis for encouraging natural pregnancy. People spoke of the joy children can bring, as well as the inability of all parents to control their offspring's futures. One forum user raised a eugenic argument, suggesting that pre-natal screening could be a slippery slope. The value of life with MND also arose in discussions, with forum users defending the value they found in their own lives (with MND) and encouraging others to reflect upon their own experiences of living at risk. This speaks to wider work on prenatal screening which highlights the complex ways that different forms of experiential knowledge inform views on disability and are mobilised in such decisions (Boardman, 2014).

Starting a family under the threat of MND appeared to engender complex feelings for those who had made this decision. One woman shared her guilt over the risk to her children, though reported that she did not regret her decision. She spoke of life as something unpredictable that should be lived to the full. Other forum users, by contrast, expressed a sense of being grateful that they did not have (biological) children.

Although reproductive technologies for preventing MND in future generations were often alluded to, they were rarely presented as alternative options to having children at risk or explicitly named. People presented variable knowledge on the availability and potential of reproductive technologies, and expressed a range of perspectives on their use, at times based on misunderstandings of how they would work (for example, confusing PGD with gene editing). Whilst forum users often seemed to promote a pro-natalist position, it is unclear the extent to which these findings point to negative attitudes around the use of reproductive technologies. This could indicate limited knowledge on

reproductive options or an unwillingness to discuss different reproductive choices in this public space.

In spite of the diversity of experiences and attitudes of forum users, forum posts included minimal overt conflict. It is worth restating, however, that the threads in our analysis saw little dialogue between original posters and other forum users who responded to these posts, with most original posters responding to the resulting threads either not at all or with a single message.

## Discussion

Several limitations of this research should be acknowledged. Our search strategy was based on keyword searching and may not have identified all relevant posts. It should also be noted that the experiences of people who use online forums are unlikely to be representative of all those affected by inherited MND. Forum users may have unmet support or informational needs or be more engaged in learning about and discussing the condition. As has been highlighted in existing literature (Saukko, 2009), we reinforce the need for further research into the characteristics of those who do and do not participate in such groups. We must also keep in mind that we do not know how responses to forum threads were received by the original poster. Although we cannot probe participants to seek clarification or develop theoretical ideas, a necessary limitation in all research using 'found' or 'naturalistic' data, this article raises several topics of interest around genetic risk.

Existing literature has both highlighted and contested the transformative effects of developments in genetic knowledge and technologies in the lives of people facing hereditary conditions (Featherstone et al., 2006; Finkler, 2010). This study provides a preliminary insight into the ways genetic risk is perceived and made sense of by people with a family history of inherited MND. Our contribution explores the role of the forum in this sense-making process, whereby people come to understand and act upon inherited MND as a genetic condition.

For many individuals, the forum was a place they turned to at key stages of their experience of inherited MND. Forum users, some with ambiguous family histories, made sense of genetic risk through tracing the disease back through relatives, at times co-constructing interpretations of risk. Secondly, people shared experiences of risk in their everyday lives; some framed MND as a 'time bomb' waiting to go off, reinforcing that families may live in a liminal or ambiguous state between health and disease (Timmermans & Buchbinder, 2010). Others drew on the language of statistics and chance, where risk was seen in terms of a game of odds or a genetic lottery, reflecting how fatalistic beliefs may be tempered by the attitude that inheritance is dictated by luck (Featherstone et al., 2006). Finally, people grappled with future decisions around pre-symptomatic genetic testing and reproductive choices, negotiating the uncertain terrain of genetic information and technologies, amidst complex and conflicting hopes and concerns (around knowing their genetic status and having children at risk of the disease). In light of these findings, we suggest that being at risk of inherited MND, as articulated on the forum, is shaped temporally through reconstructions of past intergenerational experiences and narratives, making sense of present experiences (poster's own and other family member's) and looking to the future. As articulated by Atkinson and colleagues (2013), 'Risk always contains a temporal dimension. It projects past and present into futures that are contingent on possible behaviours and outcomes'. Beyond the context of genetic risk, Jurich (2021) has shown the multi-layered

temporal dimensions of how parents caring for infants with allergies use online forums in managing risks. In such practices, as in our study, experiential and technical knowledge come together as a means for managing uncertainties.

For many forum users, a profound sense of uncertainty pervaded posts. Families affected by inherited MND must navigate multiple layers of uncertainty – around scientific developments and the future of the disease; their own genetic risk, which was often hard to quantify; and making future decisions, amidst a complex biomedical and ethical landscape. In the context of this uncertainty, the forum was a site where experiential knowledge was foregrounded in the information and advice shared between users. However, a unique aspect of the MND Association Forum is how it brings together people with experience of both hereditary and 'sporadic' forms of the disease. As Boardman (2014) found in her research on reproductive decisions around spinal muscular atrophy (SMA), different experiences or 'ways of knowing' the disease, including relationship to the person affected (or being affected oneself), disease type and severity, impact perceptions and decisions in complex ways (Boardman, 2014). The experience of witnessing, and in some cases caring for, multiple family members living with and dying from MND shaped the narratives of those with a hereditary form of the disease. We argue that this difference is crucial in how risk is made sense of in forum interactions that include people both with and without hereditary forms of the same disease.

While respondents all had experience of MND in some capacity, and some spoke of having other conditions in their own families, this remains distinct from the specific forms of knowing faced by people who had seen the disease in their relatives and faced the possibility of developing symptoms themselves. Forum users, many without a family history of the disease, often urged caution around pre-symptomatic testing and making reproductive decisions on the basis of genetic risk. The uncertainties of living at risk of MND were here reframed as hopes for alterative scenarios of non-inheritance, incomplete penetrance, late onset, or a future cure. Forum users positioned MND against other (uncontrollable) risks to highlight the impossibility of controlling life. Such points were often reinforced with statistics or through emphasising scientific progress, and MND was perceived as something that should be pushed to the background whilst all is well.

Some people with a family history of inherited MND, however, framed their risk as a matter of deep uncertainty and fear. Looking back to the experiences of relatives affected by the disease formed a vivid frame of reference for visualising their own future, highlighting how genetic risk can be experienced in the context of profound grief, loss, and trauma. Our findings reflect the dual nature of uncertainty as something that may be feared and managed, yet also welcomed as a way to maintain hope (Reed et al., 2016). It should be noted that the family history of many forum users was not displayed or articulated on the forum, which emphasises the need for further research to understand how attitudes and experiences are shaped by different forms of knowing and articulated in different interactional spaces. It is equally important to emphasise that risk is experienced in diverse and complex ways by people with a family history of MND, and navigated amidst other factors and responsibilities, including wider institutional structures, financial constraints and caring roles.

In online forum discussions, personal experiences became intertwined with scientific and genetic information, highlighting how different types of knowledge feed into understandings of risk. Risk information is refracted through families' own frames of reference, in interaction with biomedical information and other forms of knowledge (Featherstone et al., 2006), which can lead to risk being framed in a multitude of

ways, not all of which correspond to a biomedical model. This can give rise to 'distinctive vulnerabilities' (d'Agincourt-Canning, 2005), where the experiences of other family members see people at risk develop anxieties around experiencing a particular bodily sign, or reaching the age where relatives became symptomatic, reflecting research amongst families affected by Huntington's disease (Cox & McKellin, 1999; Quaid et al., 2008). Our findings thus reinforce how Mendelian theories of inheritance rarely align with how risk is experienced in the everyday lives and family relationships of people affected by inherited conditions (Cox & McKellin, 1999).

Experiential knowledge is built in part on acts of surveillance. Surveillance is a concept which brings together the temporal frames of past, present and future. Whilst the clinic is one site where surveillance happens, it also plays out within the family (Atkinson et al., 2013). Chilibeck et al. (2011, p. 1771) talk about families serving as 'living laboratories' where genetic knowledge is evaluated and tested to make sense of risk. Featherstone et al. (2006) have shown many different ways in which generations inspect each other in families living with inherited conditions: older people may look at younger generations for signs of the disease; people at risk may look at older generations to see what their future may be; and families may trace back the pattern of the disease to see where it came from, and anticipate its future trajectory. As has been well documented in literature on Huntington's disease (Forrest Keenan et al., 2007; Leontini, 2006; Richards, 2004), surveillance can take the form of monitoring relatives at risk, but also the self. Although these practices of surveillance take place outside of the forum, on the bodies of individuals at risk, our study shows how the forum formed a part of these surveillance practices, used to construct understandings of and navigate risk. In this space, people look to, or are presented with, the experiences of other families to assess their own risk and how MND may affect their family. Experiential knowledge on risk factors or early symptoms may be taken into people's offline lives and used to assess either the self or relatives for signs of the disease. The MND Association Forum is a site where multiple forms of surveillance play out across online and offline contexts, between the realms of the forum and the family.

## Conclusion

Through this research, we have explored how people with a family history of MND make sense of and negotiate genetic risk, as these practices are expressed on the MND Association Forum. Contributing to a growing qualitative literature around experiences of inherited conditions, we suggest that living with a family history of MND emerged temporally on the forum, and was engaged with through reconstructing the past, coping with risk in the everyday, and looking to the future. Experiences were crosscut by profound uncertainty, creating a space where different forms of experiential knowledge became intertwined with biomedical and genetic information. Such forms of knowledge were fed by and fed into acts on surveillance. Through surveying the self and others, risk was made sense of between the realms of the forum and the family. We have shown how the site not only provides a space for the sharing of experiences but through sharing and receiving different forms of knowledge and information with others, it may also play a role in how forum users come to understand and act upon genetic risk.

Although forum exchanges can only go so far in exploring how people understand and act upon their family history of MND, we introduce inherited MND as an area that has much to contribute to understandings of genetic risk. It is clear that questions raised

in this research warrant further attention: how do people at risk of inherited MND make sense of genetic risk amidst multiple uncertainties, a complex biomedical landscape, and changing life contexts?; how do they construct knowledge around the disease and it's hereditary implications?; and how do they make decisions around pre-symptomatic genetic testing and reproductive choices in light of technological advances which may lead to new options, and a perceived responsibility, to manage genetic risk?

With this article, we hope to lay a basis for future research with families affected by inherited forms of MND, including those who do not engage in forum communication and who are not represented in this analysis. This remains a pertinent area of study as advances in genetic knowledge and technologies present opportunities for people to understand and act upon genetic risk in new ways. This research has been carried forward in an interview study aimed at elucidating these topics further.

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