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TITLE: Evaluating a Genetic Counselling Narrative Group Session for People who have Tested Mutation Positive for the Huntington's Disease Expansion: An Interpretative Phenomenological Analysis

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SUGGESTED RUNNING HEAD: Genetic Counselling Narrative Group Sessions

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Abstract

Huntington's disease (HD) is an inherited neurodegenerative disorder characterised by motor problems, cognitive impairment and mood disturbances. Given the emotional elements of both HD itself and the testing process for it, psychological interventions may be helpful for those families impacted by HD. A stand-alone genetic counselling narrative group has been offered by one regional genetics clinic in the north of England to support people's coping following predictive genetic testing for HD. Groups are held 4-5 times per year with patients attending a group on a single occasion. This study assessed participants' experiences of attending a group using the qualitative method Interpretative Phenomenological Analysis (IPA). Telephone interviews were conducted with 12 people who had a mutation positive HD predictive test result and who had taken part in a genetic counselling narrative group session between November 2017 and February 2018. Participants were asked about their experiences of the group and any impact it had had on their lives. Four themes emerged: 'The power of the group', 'Active elements of the narrative exercise', 'Subsequent impact of the session', and 'Another voice'. Participants described the positive impact of being able to meet and empathise with others in a similar situation, the group's positive impact on their mood and future outlook as well as its beneficial impact on disclosure. While most participants were positive about the session, the final theme presented the voices of two participants for whom the groups were poorly timed. Given the sessions' generally positive impact, we recommend other centres consider offering people impacted by HD similar sessions.

Key words: Predictive Genetic Testing, Genetic Counselling, Family

Introduction

Huntington's disease (HD) is an inherited neurodegenerative disorder characterised

by motor problems including chorea, cognitive impairment and problems with mood including depression, irritability and apathy (Craufurd et al., 2015). Whilst motor problems are required to confirm a clinical diagnosis of HD, it is recognised that cognitive changes and problems with mood may precede motor onset by many years.

HD is inherited as an autosomal dominant condition. The causative genetic mutation is an expanded CAG repeat in the HTT gene encoding the Huntingtin protein. Onset is usually mid-life with disease progression over a period of 15 to 20 years (Ghosh & Tabrizi, 2018).

Predictive testing for HD has been available by direct mutation analysis since 1993 (MacDonald et al., 1993). The decision of whether to be tested may be informed by a number of factors. People may want to be tested if they plan to have children or feel distress over uncertainty; however, reasons not to be tested include concern over being paralysed with knowledge and igniting a search for symptoms (Smith, Michie, Stephenson, & Quarrell, 2002). There is no 'correct' decision to be made about whether or not to be tested, since both options have pros and cons (Smith et al., 2002).

Initial emotional responses to a mutation positive test result can include shock, anger, regret, the feeling that life is over, worry about the future, fears about discrimination, but also relief that the uncertainty is over (Theed, Eccles, & Simpson, 2018). People receiving a mutation negative test result may face survivor guilt (Decruyenaere et al., 2003). However, following this initial distress, most will adjust to their result within one to five years (Decruyenaere et al., 2003; Forrest Keenan, McKee, & Miedzybrodzka, 2015). It has been found that pre-test levels of anxiety and depression are a stronger prediction of post-test anxiety and depression than test results (Decruyenaere et al., 2003).

Given the emotional elements of both HD itself and the testing process, psychological interventions may be helpful for families impacted by HD. While there is a history of such interventions (Bonelli, Wenning, & Kapfhammer, 2004; Kloos, Fritz, Kostyk, Young, &

Kegelmeyer, 2013; Silver, 2003), more work needs to be done (Theed et al., 2018). One qualitative study found that those who had tested mutation positive were open to the idea of talking therapy and preferred this to anti-depressants, even if they had had bad experiences of therapy in the past (Theed et al., 2018). Acceptance-based interventions as well as systemic, family group-based work, led by genetic counsellors have been recommended for families impacted by HD (Maxted et al., 2014).

Access to counselling support is important as it could instill hope in people living with HD (Theed et al., 2018). Predictive test guidelines for Huntington's disease recommend post test counselling support is offered to all individuals regardless of test outcome (MacLeod et al 2013).

Narrative therapy is an approach which facilitates existing resilience and strengths as well as encouraging hope (Hedtke, 2014; White & Epston, 1990), and has been shown to be useful for people living with HD or knowledge that they carry the mutation. (MacLeod, Moldovan, Stopford, & Ferrer-Duch, 2018; Stopford, Ferrer-Duch, Moldovan, & MacLeod, 2019). Narrative practices include naming the problem that an individual or group is dealing with, so that it is the problem which is named as *the problem* rather than the person (Hedtke, 2014). The Narrative model is committed to detecting the preferred stories of people that may become overlooked in times of difficulty.

A genetic counselling narrative group was launched in 2015 to help those who had had the genetic test for HD to build resilience and find new ways of making sense of their results. This group is offered ~ 5 times per year as a clinical service to families known to the Genetic Family Register Service at Manchester Centre for Genomic Medicine. Individuals are informed about the possibility of participating in a narrative group session through their

genetic counsellor. The group is facilitated by a clinical psychologist and a genetic counsellor trained in this approach. This implementation of the narrative approach uses an adaptation of the Tree of Life exercise (Ncube, 2006) to facilitate a discussion about participants' strengths and support systems. As currently implemented, individuals participate a single time in the narrative group. See Box 1 which describes the process involved. The purpose of this qualitative study is to evaluate participants' experience with this genetic counselling narrative group to determine whether participating in a single genetic counselling narrative group is perceived as helpful. This is important as it will look at the feasibility of integrating a stand-alone group session in to routine genetic counselling practice with a view to facilitating adaptation.

Insert Box 1 here

Method

Participants

People who had received HD predictive test results and had taken part in a genetic counselling narrative group between November 2017 and February 2018 were invited to participate in the research. Based on these criteria, a total of 14 individuals were eligible to participate in the study. Individuals were contacted by a member of the research team about participation in the study 2-4 weeks after the sessions. It was felt that this timing allowed for some reflection on behalf of the participants and provided a 'cooling off' period. A total of 12 people were recruited from three narrative group sessions. Although we initially planned to include people who had tested positive or negative, given the time frame of the study, and the

need for a homogenous group for IPA analysis, we eventually focused on those people who had tested mutation positive.

Informed consent for participation in the study was obtained by a member of the study team who co-facilitated the group session. All interviews, which took place over the phone between December 2017 and March 2018, were conducted by JSp, a qualitative researcher not involved with the group sessions. Interviews included questions about the narrative group session itself and its impact (or not) on participants' lives (interview guide available as Supplementary file 1).

Ethical approval was granted 5/9/17 (REC reference: 17/NE/0290). Participants were told that they were free to stop the interview or withdraw their data at any time should they wish.

Data Analysis

Interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) was used to explore how participants experienced the narrative group. Qualitative approaches to evaluations of interventions such as these are useful, since they offer participants the chance to be more critical than they could be on feedback forms (Shek, Ng, & Tsui, 2010), and mean that key stakeholders can be a part of improving those services (Nabors, Ramos, & Weist, 2001). IPA is well suited to complex topics about which little is known (Smith et al., 2009), so is a good fit for the topic.

Interviews were transcribed verbatim. Transcripts were read and re-read, and then analysed line by line. Emergent themes were combined into tables of themes for each participant. These tables were then compared across cases, looking for convergence and divergence. A master table of themes for all participants was drawn up based on this comparison and was used to guide the writing up (see Table 1). Analysis continued during writing (Smith et al., 2009).

Analysis was undertaken by the first and second authors who also wrote the first draft of the results section. In this way, a separation was maintained between those facilitating the group session offered through the clinical service and those evaluating it. All authors contributed to the introduction, method and discussion sections.

>>>>>>Table 1 here<<<<<<<<

Results

A total of 12 people were recruited from the three narrative group sessions. Interviews lasted between 12 and 42 minutes (mean = 27 minutes). Participant demographics are shown in Table 2. All participants were given pseudonyms in this paper.

>>>>Insert Table 2 here<<<<<<

Analysis uncovered four major themes: ‘The power of the group’, ‘Active elements of the narrative exercise’, ‘Subsequent impact of the session’. A smaller but important theme also arose: ‘Another Voice’, the experience of two participants for whom the session was poorly timed. It should be noted that one of these two participants also described some benefits as well as some problems.

The power of the group

Eleven of the 12 participants talked about the benefits of meeting others impacted by HD.

First opportunity to meet other people living with the HD gene fault

This was the first opportunity many participants had had to meet people outside their own families who were impacted by HD. For Hannah, a strength of the group was meeting others in the same situation, emphasising how this shared HD status highlighted commonality:

It was really positive to meet with other people sort of in the same situation as myself, cos obviously, it's a bit of a unique situation.

For Lucy, meeting other people whose families were living with HD meant that she no longer felt as though her family were the only people impacted by the disease:

It's nice to reach out and just, you know, understand that you're not kind of the only family that are going through the same thing, you know.

Lucy describes here how a sense of connection with other people combats the loneliness and isolation of feeling like the “only” family impacted by HD.

Like most of the participants, Dawn knew people within her own family who had HD. However, meeting other people who were asymptomatic was a new, reassuring experience:

Everybody in my family is older than me who's got the illness. Is like, quite far, ahead. So, you never really see people who are like, not as bad.

Vital peer support

Participants were appreciative of the peer support element of the session. Adam highlighted the reciprocal nature of the group:

To also hear how, um, they discuss things with their friends if they're the type that keep it, you know, um, below the radar [...] and it was nice to express how I've dealt with certain situations as well, and it shone a light on their lives so to speak.

Adam was interested in hearing different disclosure strategies, and felt his own approach had the potential to illuminate a new disclosure option for others, illustrated by his metaphor of shining a light. This language suggests that the session enabled Adam to position himself in

the role of teacher, which seems likely to have a positive effect on his self-esteem. Hannah focused more on the way in which the session allowed her to support others:

I think just sort of having the opportunity to sort of support all the people taking part, so if they weren't sure you could say oh well, what about that [...]. So that kind of collaborative approach I think is erm always a good thing, isn't it?

Hannah appreciated the opportunity to give something to others. Hannah's use of the word 'collaborative' here suggests the power of peer group support.

Empathic bonds with others living with the HD gene fault

Many discussed feeling a connection with the other members of the group despite having only just met them. Karen spoke enthusiastically about forming a bond with other group members:

When I was there, amongst those people who were in the same boat or situation as me, there is the power of connectivity. The power of the group, the power of not being the only person.

Karen uses the word power three times here, emphasising how meaningful this situation was for her. They are a team, not one isolated person; together, they are connected and have power.

For Beth, the knowledge that others are physically close to her relieved her isolation:

He's like round the corner, really. [...] even if I don't speak to anyone again, not that I'm gonna go saying that, I mean, but it is nice [...] Knowing that I'm not alone.

There is a sense of comfort and contentment that arises from this quote.

Maria cited various different elements of meeting others who had tested positive that were beneficial to her:

So interesting, ah, partly because there were points of connection, but also when there weren't, there was something to learn from it. And, um, of course (pause) you know, you can't feel anything other than sympathy and compassion for other people, because you absolutely do, because you empathise with what they're going through.

Meeting the group was intense for Maria and involved feeling connected and educated as well as feeling sympathy, compassion and empathy. However, Maria's language is interesting; she separates herself from the group by saying "other people" and "they" rather than we and us. In addition, her sympathy suggests an element of feeling sorry for others. This may be because Maria's experience of HD was different from others in the sample. Maria hadn't been close to her father, who has HD, since she was a child, and so hadn't witnessed the disease. This may have made HD feel unreal for her; however, meeting others allowed Maria to hear more about the reality of HD, something she experienced as positive:

It was just brilliant hearing other people's experiences.

Beneficial comparison with others living with the gene fault

Many participants compared their own experiences with those of others in their groups and described this comparison as being helpful. Elaine experienced high levels of distress following her test result. She talks about how inspiring it was for her to meet others:

I was like looking at everyone in awe thinking wow, you know, they're all still here, they're still alive, they're still getting up in the morning.

Elaine finds it motivating to see others in a similar position to her who appear to be coping well. Her language is suggestive of a spiritual awakening.

Fiona also finds a process of comparison helpful:

My dad started getting sort of physical symptoms in his, I'd say mid 50s. Err, and my grandad sort of his early 60s, so to see people that were similar, or slightly older and actually, they still look OK (small laugh). Erm, was reassuring.

Fiona finds it reassuring to meet other people in the group who remain asymptomatic despite being about the same age as members of her family when they got symptoms.

Graham discussed a positive impact of comparing himself with those apparently doing better or not as well as himself:

Some people who I thought dealt with it better than me, and other people who hadn't dealt with it better than me, and seeing different age groups and, erm, one thing that stuck in my head was a woman who, who still doesn't have it, but she was diagnosed years ago. [...] that's a big one for me, so I can just get on with my life, and the people

who did better than me, in, in my opinion, obviously can take something that they do that helps.

Meeting someone who was older and had not developed symptoms was reassuring for Graham as well as Fiona.

We have seen that comparison with others in the group who were older and still living well was helpful for participants. However, it is important to note that one of those older group members, who was inspiring to others, experienced the session in a different way. Isla did not feel the same benefit from meeting the others in her group:

That doesn't bother me [...] I didn't feel it was right for me really.

This raises an interesting conundrum. Isla's presence in the group was beneficial to several other participants. However, she herself did not find the session relevant.

Active elements of the narrative exercise

Nature of the tree

Participants talked about specific elements of the tree of life exercise, which they found beneficial. These included the gradual nature of the exercise, the guided, systematic structure of the session and the metaphor of the tree itself.

The narrative exercise starts with a discussion of everyday activities and works up towards more sensitive areas such as hopes, dreams and legacies. Beth found that this gradual funneling of topics allowed her to feel safe sharing with the group:

It was nice to just start off with little things, you know, little things that like, little things that don't mean, you know, what I mean, and then like right at the end it's like big things that mean everything to you. Do you know what I mean?

Similarly, Carrie appreciated the fact that there was no pressure to share at first, but found that hearing others speak enabled her to share also:

You just had to write it down at first, and weren't sharing anything. And then eventually, once people started to speak about things that they put down there, then you kind of got the confidence to actually speak about it then.

Adam found the systematic nature of the tree exercise appealing:

I think in simple terms, but things belong in boxes, and, um, in nice to put, certain things in certain aspects into boxes.

Elaine enjoyed the guided nature of the discussion as she felt that this gave the session a focus:

The discussion was kind of guided, although she gave you time to speak, and then go off on a bit of a tangent, it was still good, because it kind of kept it in the direction of conversation,

which was really good, you know. The conversation wasn't going all over the place, it was actually going somewhere.

Elaine's repetition of the word 'good' demonstrates how positive this was for her.

Hannah felt that the metaphor of the tree was coherent and so worked well:

It makes a lot of sense, obviously you've got a family tree and, I, the roots and the erm, the legacy and the history and it's a very organic thing as well, a tree.

Positive legacy of tree exercise

Participants talked about how particular features of the adapted tree of life exercise resulted in positive thoughts and emotions.

For Hannah and Adam, certain stages of the tree exercise were a reminder to think about and spend time with family:

Hannah: Remembering, erm all the elements of your own family and (pause) history and, erm, sort of additional story that sometimes you don't, sort of have at the forefront of your mind? Obviously, I know my mum, your dad and I think about them every day but (pause) it's just going into that extra level of detail which is something quite comforting in that.

Adam: I can't remember what part of the tree it related to, but um, one of it was, um, to make more time and to speak to, um, to spend more time with um, like, the older generation, so to

speak. Um, of, of my family, like me aunties, me uncles, and um, like me dad and ah, and, and that.

Maria found that the various stages of the exercise were a warm reminder of the good side of life, illustrated by her use of positive language such as ‘wonderful’ and ‘lovely’:

What are your roots, the trunks, the, the branches, the leaves and all of that and how (pause) it kind of, it, it was a reminder about the stuff (pause) that is, um positive and good. Um, and it was wonderful. It's lovely (laughs).

Fiona, who had decided not to have children as a result of her HD status, particularly found the ‘legacy’ stage of the exercise led to positive thinking. Although she shared a fairly small legacy during the group (being heir to a family biscuit recipe), the exercise triggered more meaningful realisations for her later on:

We chose not to have kids, erm (pause) 20 odd years ago and also thinking about that legacy and things like that, you know, what will you leave behind, and actually (pause) thought I (laughs) although I mentioned the cookie recipe and things, which I thought well, there is actually a lot more to leave behind than that, and, and that's really nice and good.

Subsequent impact of the session

Ten participants said that the session had had an impact on them or had instigated a change.

Session boosts mood

The majority of the participants had a positive experience of the group. Fiona described the positive impact the session had on her thinking in the weeks following it:

Just a way of looking more positively at stuff, and actually, realising that (pause) it's, like you say, it's not doom and gloom.

The session helped Hannah reaffirm her own humanity:

Made me, erm, realise that [...] I am not the illness, and I don't want to be defined by that and I can be me first and that sort of is just part of who I am.

Here, Hannah rejects the illness role that the knowledge of HD has previously enforced on her and reclaims her sense of self as a holistic and multi-layered person.

For Graham, the impact of the session was such that he was now focused on positive interactions with others, rather than rumination about his positive test result:

Go out more (laughs), like, with your wife, with your friends and, not sit in and think about it. Err, occupy your mind. [...] it's just doing something positive and for yourself and, and for others sometimes and not just sitting here thinking about what's happening, when it's gonna happen, am I shaking am I not, you know.

This quote suggests Graham had previously spent a lot of time ruminating. Now, his focus is more on quality time for himself and positive interactions.

For Maria, the session facilitated an attentiveness that she found beneficial and her language here is effusive in its praise:

That process that you took us through was brilliant for that. Erm, because it made me notice stuff that I had done that I hadn't really thought too much about. And that was wonderful, it felt like a bit of a gift actually, I was really happy afterwards.

Impact of the session on disclosure

Several participants discussed the fact that the session made them feel more able to disclose their HD status to others. Dawn was influenced by another group member, saying:

There was a lad saying about how he just openly tells everybody? Straight away? [...] He said it was really easy to do, so (pause) I don't know, I was kind of thinking about maybe, you know (long pause), telling a few, telling another person maybe.

Although Dawn is indecisive, she went on to talk about having a specific person in mind who she wanted to tell. By modelling this other group member, Dawn may be able to overcome her anxiety about telling others and share her HD status with her friend.

Carrie went further, describing a shift between not telling many people about her HD status to feeling that she could tell 'anybody', demonstrating the impact of the session.

There's not very many that do know [...] but, I feel like now I could probably speak to, anybody about it.

Graham went further still. In the time since the session, he had told his counsellor about his positive test result, something he had only hinted at before:

I think I'm more open with my counsellor than I would have, you know, like, and tell them the whole truth and not, bits and bobs.

The reaction that Graham had from his counsellor demonstrated her absolute support, suggesting his disclosure, enabled by the session, was helpful:

She was very nice, and you know (small laugh), I'd even say she got upset and she, she's just there for me all the time and anything I need.

Freeing impact of the session

Several participants described a freeing impact of the session. The session gave Hannah the time and space to absorb her very recent test result, and permission to be upset about it, something with which she had previously struggled:

Help you, erm, feel OK for not being OK.

The session appeared to have opened Graham's future. He said:

Just makes you think more, in depth about it and not just (pause), you know, yourself and it broadens your horizons.

For Fiona, "*the future was always quite bleak*". However, she is now able to say:

He [partner] said well you know, what did you put down as wanting to do in the future? And I said, you know, just travel round Europe.

The ability to go travelling with her partner epitomizes freedom and stands in sharp contrast to the restrictions imposed by HD she had previously seen her future as holding.

Another voice

The theme ‘Another voice’ captures the experience of two participants (Karen and Isla) for whom the session was recalled as less beneficial. This theme stands alone, with no sub-themes.

Karen and Isla questioned the timing of the group. They were the two oldest members of the group and both had been diagnosed around 20 years before the session, which may have had an impact on how relevant it felt for them. Isla didn’t feel the session was suitable for her at all:

I still think it’s an age thing, whereas I, I really didn’t need that at all.

So Isla suggests the group was less useful of someone her age. While Karen suggested that the session might be more suitable for people who had just had their genetic test for HD:

Perhaps it may be a very useful thing for a person who’s just been diagnosed, there and then, to remember (pause) what anchors them (pause) to, to, to this world.

This is striking language, illustrating how impacted people may feel following their predictive test for HD, and suggesting the potential the session has for people at this time of upheaval.

In addition to her uncertainty about the timing of the session, Karen said that the day after it, she felt “*absolutely exhausted*”.

It was sort of demoralizing to be left (pause), erm, with the uplift and [...] sharing things with people and then back to earth with a bit of a bump the next day.

Karen’s use of the word demoralizing suggests she felt hollow and abandoned after the session. Her use of the phrase “back to earth with a bump” suggests that reality felt low and difficult compared to the “uplift” of meeting and connecting with others during the session.

Discussion

This qualitative study explored how twelve participants who had tested positive for the Huntington’s disease mutation, experienced a novel standalone group session integrating narrative practices and genetic counseling. Most of the participants were very positive about their experience adding to the evidence of the acceptability of genetic counselling narrative groups post predictive testing for Huntington’s disease. (MacLeod, Moldovan, Stopford, & Mariangels Ferrer-Duch, 2018; Stopford, Ferrer-Duch, Moldovan, & MacLeod, 2019). The research interviews and analysis for this study were conducted separate from the clinical team by independent IPA researchers (JS, JSp). Taken together the studies show that participants have found the groups a safe environment in which to connect and to discuss individuals’ ways of resisting the challenges of Huntington’s disease in their lives. A new important finding in the current study was that participants found it easier to talk about HD with family and friends after taking part in the group. This is important to explore further in terms of the utility of narrative practices as difficulties in family communication have been highlighted as

problematic, not just in HD, but other genetic conditions (Metcalf, Plumridge, Coad, Shanks, & Gill, 2011).

This innovative approach to facilitate adaptation following predictive testing for HD differs from other types of support groups in several key ways. Firstly, participants attend a single standalone group session i.e. it is not set up to provide ongoing support. Secondly the session is structured around a narrative exercise and a therapeutic conversation. Thirdly a genetic counsellor, usually already known to the patient, co-facilitates the session with the clinical psychologist. The main findings in the current investigation are discussed below.

Participants talked about the importance of meeting others in their situation. Lucy described a previous sense that hers was the only family in the world living with HD, a finding reflected in another IPA paper, where participants described feeling that it was ‘us against the world’, as other families could not understand the challenges facing those living with HD (Maxted et al., 2014). Empathic bonds between our participants were also described. Similarly, Ulanowski and colleagues (Ulanowski, Danzl, Schwartz, & Reed, 2017) have described the importance of community arising from their study, which qualitatively evaluated the impact of a yoga-based intervention with people living with HD.

Participants discussed the benefits of being able to engage in peer support, both in terms of receiving and offering support. A content analysis of an online HD support group (Coulson, Buchanan, & Aubeeluck, 2007) found that informational and emotional support were commonly shared, suggesting there is a need for these within the HD community. Where we believe the genetic counselling narrative sessions differ and are novel, is in providing a therapeutic framework that uses narrative questions to invite participants to look at their lives from a variety of perspectives as a way of generating hope or to support their

preferred values. Through focusing on how these conversations are making a difference, we hope this will continue to support more open communication in families.

Participants found it beneficial to compare themselves to others in their groups (Arigo, Suls, & Smyth, 2014; Festinger, 1954) to boost their outlook. There is robust evidence to demonstrate the benefits of social comparison for people living with chronic and/or life-threatening illnesses (Heaton, 2014; Martinez et al., 2018; Taylor, 1983; Taylor & Brown, 1994). It therefore appears that providing people living with HD opportunities to meet and compare themselves with others in the same situation is to be recommended.

It has been frequently reported that some people experience distress in the period following the predictive testing for HD (Decruyenaere et al., 2003; Forrest Keenan et al., 2015; Theed et al., 2018). The genetic counselling narrative group session seems well-placed to help people from families living with HD boost their mood and so help to combat distress.

The impact of the session on participants' level of disclosure is an exciting finding. A body of literature has looked at disclosure of HD status to employers, insurers and social contacts, as well as any discrimination arising from that disclosure (Erwin et al., 2010; Penziner et al., 2008; Williams, Erwin, Juhl, Mills, et al., 2010; Williams, Erwin, Juhl, Mengeling, et al., 2010). Findings suggest that while people living with HD face some discrimination from insurers and employers (Erwin et al., 2010), fears about discrimination tend to outweigh instances of it (Erwin et al., 2010; Penziner et al., 2008). Some have discussed social discrimination as a result of disclosing their HD status, such as being rejected by partners (Penziner et al., 2008; Williams, Erwin, Juhl, Mengeling, et al., 2010). However, others have reported potential benefits, such as relatives becoming more attentive (Penziner et al., 2008) and being able to retire earlier (Williams, Erwin, Juhl, Mills, et al., 2010). Disclosure of HD status is a complex decision which will be different for each person.

However, since disclosure brings benefits to some, an opportunity to discuss it, as offered by the group session, seems prudent.

The freeing impact of the session is another novel finding. Existing research suggests people may feel hopeless or trapped following a positive test result (Decruyenaere et al., 2003; Maxted et al., 2014; Theed et al., 2018). The fact that several participants saw the session as opening doors for them suggests that other centres consider offering people impacted by HD the chance to take part in similar sessions.

Reflections

While this evaluation of the narrative session was mostly positive, two participants didn't find the session so helpful when interviewed afterwards. Both talked about the timing of the session. Given the finding that many who have been tested adjust to their results within one to five years (Decruyenaere et al., 2003; Forrest Keenan et al., 2015), it seems possible that the session may work better for those who have been tested more recently. This requires further exploration however, as researchers have also highlighted potential longer-term impacts of predictive testing (Timman et al 2004).

While the session was not so relevant for Isla, hearing about her experiences was beneficial for others. We suggest that this adds support to the evidence for the benefits of peer support with a therapeutic structure for people living with HD (Coulson et al., 2007). Perhaps HD specialists who are aware of people continuing to live life according to their preferences a long time after their results could consider working with them to deliver peer support to those who recently had their test. This may address the reported shortfall in support following test results compared to the genetic counselling offered before the test (Forrest Keenan et al., 2015).

Practice Implications

This study has shown the potential for people who have tested positive for the HD mutation to derive benefit from a single genetic counselling narrative group session. This is an important finding particularly for publicly funded services such as the NHS. The finding that there were impacts after the session including a willingness to talk more openly about HD has direct practice implications as difficulties in family communication can lead to strain on families and their wider social network, the effects of which may go unchecked for years (Metcalf et al., 2011). Narrative practices as a collaborative approach where the ‘problem’ is seen as external to the person could be viewed as consistent with the aims of genetic counselling. Future work could include a wider reach for example in the training of genetic counsellors and narrative counselling supervision.

The ‘power of the group’ emerged as a major theme in this study. Whilst acknowledging other important ways for patients to meet as a group, in particular the tremendous work of the lay organisations, there are many people who never attend a lay support group or who find it difficult talking about the genetic condition in their family. The Genetic Counselling Narrative Group serves a different and complementary function through involvement of a genetic counsellor known to the family, and the adoption of a structured narrative exercise. As the number of genomic tests increases, multi-disciplinary working and new models of service delivery that has a therapeutic underpinning is essential for the benefits of patients and families. More research is needed to see how the Genetic Counselling Narrative Groups may be adopted for other genetic conditions.

Author contributions

Johanna Spiers and Jonathan A Smith made substantial contributions to the design of the qualitative research study as well as the acquisition, analysis and interpretation of the data and drafting and revising the paper.

Mariangels Ferrer Duch, Ramona Moldovan, Jay Roche and Rhona Macleod developed the genetic counselling narrative group, contributed to the design of the study and made important contributions to the write up and revising the paper.

All authors gave their final approval of the version to be published.

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Compliance with ethical standards

Disclosures Some details have been changed to protect the participants' identity

Conflict of Interest Johanna Spiers, Jonathan A Smith, Mariangels Ferrer Duch,

Ramona Moldovan and Rhona Macleod declare that they have no conflict of

interestHuman Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (international and national) and with the Helsinki Declaration. Informed consent was obtained from all participants for being included in the study.

Animal Studies No animal studies were carried out by the authors for this article.

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Box 1: Genetic Counselling Narrative Group Exercise

Box 1

Each genetic counselling narrative group session has between four and eight participants. The groups participate in an adapted Tree of Life exercise (Ncube, 2006) led by MFD, a clinical psychologist, with support from RMc, a genetic counsellor. Participants are shown a large painting of a tree and told that they will be asked to use this tree as a framework to think about their own lives.

The adapted Tree of Life exercise supports people to develop goals around where they prefer their lives to go. It is about encouraging people to connect with their existing skills and resilience and to experience a stronger sense of purpose. The exercise enables a sharing of problems in a safe context.

MFD talks the participants through the different elements of the tree picture and encourages participants to write words or phrases from their lives which are relevant to each stage on post-it notes. The notes are stuck to the tree, and MFD then facilitates a conversation with participants about these aspects of life and what they mean to participants.

Tree of Life stages:

1. Ground. Here, participants are asked to write down some of their daily activities and things that are important to them.
2. Roots. Participants are asked to think and write about where they came from. They can think about their ancestors or other special places such as locations from childhood.
3. Trunk. Participants write about their skills and abilities and what they are good at.
4. Branches. This is about participants' hopes, wishes and dreams for the future.
5. Leaves. Participants are asked to consider the people in their lives that are important or have taught them important things; people that might be alive or may have passed away.
6. Fruit. This section is about legacies and messages that have been left to participants from important people or ancestors; e.g. gifts of being loved and acts of kindness.

Although HD is not built in as a direct element of the tree exercise, this narrative approach to discussing participants' experiences allows for conversation about HD and its impact to arise organically. Groups are intended to make visible participants' stories of hope and strength.

Table 1: Themes and sub-themes

Theme	Sub-theme
Power of the group	First opportunity to meet other people living with the HD gene fault
	Vital peer support
	Empathic bonds with others living with the HD gene fault
	Beneficial comparison with others living with the gene fault
Active elements of the narrative exercise	Nature of the tree
	Positive legacy of tree exercise
Subsequent impact of the session	Session boosts mood
	Impact of session on disclosure
	Freeing impact of session
Another voice: the experience of two participants for whom the session was less beneficial	

Table 2: Participant demographics

Name	Age	Years since test	Other family members with HD
Adam	33	10	Parent
Beth	31	11	-
Carrie	36	12	Parent, aunt, cousins
Dawn	38	6	Parent, aunt, cousins, sibling
Elaine	49	3	Grandparent, parent, uncle
Fiona	38	18	Parent, grandparent
Graham	31	1	Parent
Hannah	35	<1	Parent, grandparent
Isla	67	21	Parent
Karen	59	19	Parent, sibling
Lucy	27	5	Parent, aunt, grandparent
Maria	48	7	Parent, uncle, sibling