

Three possible futures: patient decision making regarding predictive genetic testing in the clinical genetics setting where there is little or no current utility

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Background

- Ambivalence is defined as having two opposing feelings at the same time.
- The patient in the genetics clinic may have felt ambivalent towards having a predictive genetic test for some time, and may also still be feeling this way.
- Ambivalence is often psychologically unpleasant (Reich & Wheeler, 2016), leading to a desire to resolve this ambivalence by making a decision or taking action.
- When helping a patient resolve ambivalence regarding changes in behaviour, a technique called two possible futures is used. This is likened to '*a hypothetical look over the fence*' (Mason, 2019).
- Aim: to explore how imagining possible futures is used with patients deliberating the decision to have predictive genetic testing where there is little or deferred clinical utility.

Reich, T. and S. Wheeler (2016). "The good and bad of ambivalence: Desiring ambivalence under outcome uncertainty." J Pers Soc Psychol **110**: 493-508.

Mason, P. (2019). Health Behavior Change: A Guide for Practitioners. Poland, Elsevier.

Participants

- We recruited 36 participants, who were at risk of Huntington's disease (HD), BRCA1/2, or deciding whether to undergo pre-natal testing.
- This presentation focuses on participants contemplating predictive testing for HD (n=16).

Recruitment

- Participants were recruited from 4 UK regional genetics services via a referral from the a genetics health professional.

Methods

Data generation

- Clinic consultations, reflective diaries and interviews.
- Clinics are well documented, however, reflections have not been documented in such a systematic way before.

Analysis

- Deductive thematic analysis.

Methods

Researcher influences on analysis

- I found reading and analysing the diaries distressing, as the content was often raw and emotional. This may have affected how I analysed the data and the conclusions I have drawn, although the findings have been discussed with the wider researcher team.
- This also highlights the importance of recognising that qualitative researchers may be at risk of ‘vicarious trauma’, which may affect their mental wellbeing (Branson & Bixby Radu, 2018). My response was likely amplified by working alone, during lockdown conditions.

Branson, D. C. & Bixby Radu, M. Do Qualitative Researchers Experience Vicarious Trauma? And, does it Matter? *Journal of Sociology and Social Work*. 2018;6(1).

Findings

Focus for today's presentation

- 6 participants at risk of HD who had completed reflective diaries, four female, aged 18-45

Three possible futures

- Do not have a test and live with uncertainty
- Have a test and receive a positive result (inherited the faulty gene)
- Have a test and receive a negative result

Findings

Almost all participants said they were hoping for the best whilst also preparing for the worst:

"I like to hope for the best, but prepare for the worst." (Diary - P19_f_25-30)

"I tend to plan for the worst and hope for the best." (Diary - P5_F_40-45)

"Sometimes I feel that I don't have the illness. But at the same time I'm trying to make myself ready for the worst." (Diary - P10_F_25-30)

"I have set myself up for the worse possible news, but still have a glimmer of hope in the back of my mind."
(Diary - P14_M_25-30)

"Deliberately blocking out the good results so that it doesn't give you false hope and upset me even more."
(Diary - P2_M_40-45)

Discussion point: Participants may be creating ambivalence to protect their feelings from a unfavourable outcome (Reich & Wheeler, 2016).

The unpleasantness of ambivalence

“When I do start to thinking about it, it's quite unpleasant. Because I still can't fathom the idea of it being 50% chances. And the two scenarios going through my head about being given the result are superimposed on each other. I've had a parallel universe version of myself experience one side of it. And then me experience the other side. And then both memories have been placed on top of each other and they're playing out exactly the same way. I'm completely ambivalent in this. Very unpleasant. It's probably one of the crappiest odds you could ever come across.”
(Diary - P2_M_40-45)

“I believe I am relying on the results of this test whether they're positive or negative to give myself the kick up the arse that I need to maybe make myself a better person in some way or another. Whether it's for X amount of years or to plan for the rest for my life or whatever.” (Diary - P2_M_40-45)

Discussion points: This participant describes the unpleasant feeling he experiences when holding two futures in his mind simultaneously. The 50/50 odds make it impossible to make any distinction between the likelihood of either future becoming a reality.

Receiving the results, which ever future they reveal, appear to offer some respite from this unpleasantness and a 'push' toward self improvement for this participant.

The unpleasantness of uncertainty

“During this appointment I had a physical exams, during the days prior and the weeks after I was very away of all movements trying to diagnose any twitch or movement. I know this isn’t useful but I feel that my brain was trying to reduce the uncertainty.” (Diary – P14_M_25-30)

*“Angry - Feel really annoyed that I have lived my whole life with a cloud following me and that there was no needed [received results, which were negative], the risk has affected my life choices and while this news is brilliant for my future is only puts me at a parity with the majority of people who weren’t at risk.”
(Diary – P14_M_25-30)*

Discussion points: Like the previous participant, P14 is describing something that almost all the participants discussed and that was looking for or experiencing possible HD symptoms. This appears to reduce the uncertainty, making one future more likely.

This participant also described regret at living with uncertainty for so long, which may only be experienced due to him receiving a negative result.

Future 1: do not have the test and live with the uncertainty

“I'm looking into the future and it's all a bit cloudy at the moment. And that might be more stressful than the actual end result, whichever way it goes.” (Clinic - P10_F_18-20)

“I would rather be worrying for a reason than every time you drop something, forget something, trip over, do something. Am I getting old, is there something else wrong with me, or have I started getting Huntington's? I'd rather be factoring it in for a reason or not. And it becomes a constant worry in that sense, in the back of your mind all the time, and I'd rather it be there for good reason.” (Clinic - P5_F_40-45)

Discussion points: There were only a few instances of imaging this future and those only appeared in consultations not diaries.

Many patients that have got to the point where they are speaking to a health professional have probably made the decision to get tested.

Before they have the test, patients are living out this future, so it is tried and tested.

Future 2: have the test and receive a positive result

“Reviewed the HD forum, reading the comments about the difficulty that people are having looking after their partners. This led me to worry about the impact on my wife. Discussed with her.” (Diary - P14_M_25-30)

*“Virtually everyday the HD situation crosses my mind. Usually it's the same stuff, is this a symptom? Do I only have potentially 20 good years left? Do I need a pension? What will my life be like? What care will I need to arrange?”
(Diary - P5_F_40-45)*

“After I got the letter for my HD appointment I decided to go deep with some of my HD thoughts, and tackle death and end of life. They really filled me with a dread, and I just wanted to tackle them head on to remove the sting. I decided to find a more mature idea than suicide by morphine and relinquish some control there.” (Diary - P19_F_25-30)

“Realisation I may have to tell more people and I would be ‘labelled’ for the rest of my life – my life won’t be my own, remain under medical scrutiny, potential medication, disability, will have to ‘give up’ on some things. Hard to accept when I consider my life to be really beginning.” (Diary - P1_F_25-30)

Future 2: have the test and receive a positive result

“We’re making sure you know what you’re getting yourself into in terms of [marrying] me, it could potentially be a case where he could be [taking] care of me in my thirties or forties.” (Clinic - P1_F_25-30)

“Having the reasonable adjustments and trying to stay in work as much as possible, would be good, but then I think with the kind of interacting element of my role, I would probably have to stop work sooner, compared with other roles, but they identify when it’s appropriate to retire on ill health and I don’t think they will try and force me into a role that I wouldn’t do.” (Clinic - P19_F_25-30)

*“I love doing stuff with my hands and I fix cars and do woodworking and I’m worried that will go out the window. Seeing my Dad used to do a lot of handiwork and he liked to do aircraft modelling and he can’t do it anymore.”
(Clinic - P2_M_40-45)*

Discussion points: This future was the one most imagined in clinic consultations and diary entries.

Is taking patients through such vivid imagined futures helpful? It may be unethical to not take them through this.

People in general have a tendency to over estimate impact of negative consequences - impact bias (Peters et al., 2013).

Future 3: have the test and receive a negative result

“I am trying to imagine my reactions to a good or a bad results. I really worry about how bad results could affect my life now I am trying to focus on different things just not to think about it. But I feel bad inside as it seems like no one cares about my feelings at the moment. I tried to speak to my dad but he told me that he hope that it will be ok and topic has ended the same with my partner.” (Diary – P10_F_18-20)

“And in one case, it's a good result and I sit there and I'm ... I imagine how upset I'll be, how relieved I'll be and how celebratory I'll be. But then, in the back of mind I'll ... it says, don't get your hopes because it might not be.” (Diary – P2_M_40-45)

“Even though she was as supportive as she could be and helped me get her genetic test report. She would have been so happy if it is a negative result. She's only been gone a few months and still at times I can't believe she's died.” (Diary – P5_F_40-45)

Discussion points: There were very few examples of participants imagining a future with a negative result.

It may be that participants in this sample could not allow themselves to think of this future as a possibility or discuss it at least.

Other's influence on shaping these imagined futures

“My dad was ill from when I was quite young due to violence and aggression. So, once a week we used to pop down to go and see him in the supported living place. But it was, to be honest it was difficult to go and see him, cos every time we saw him he seemed to be a bit worse.” (Clinic - P10_F_18-20)

“My mum is only 40 and she can't talk no more, I am really scared of that.” (Diary - P10_F_18-20)

“I find it surprising that people in the HD field here in [place] don't seem to know about the hospital and how amazing it is. They have a huge range of therapies and activities on site with lots of outings and trips which made such a difference to Mum. She went from living like a tramp in her home to starting a whole new life and trying new things. It would be somewhere I'd like to go if I have HD and I reach the point of needing full time care.” (Diary - P5_F_40-45)

Discussion points: Every participant knew at least one relative with HD, but not all these experiences were negative.

When some patients have extensive experience with a relative(s) is it necessary for them to be encouraged to imagine a future with HD?

- Participants explored their fears in vivid detail in their diaries compared to how they were discussed in clinic with their health professional.
- Health professionals may feel that they have a responsibility to insure the patient has confronted and fully imagined what their future would look like if they received a positive result.
- To what extent should consultations in clinic focus on hope? As this quote demonstrates, often discussion on clinic is only focused on a positive result:

“And it’s what, what people want generally, and so our discussion tends to focus a bit more on what if it’s not a good result. because having a good result is usually less problematic.”
(Clinician)

- What can make the process of coming to a decision and taking the test easier/less distressing/psychologically unpleasant? Or is the distress/unpleasantness a permanent artefact of this particular test?

Future analysis/research

- Relate stage in process to reflections.
- Explore interview data.
- How do discussions with others shape these futures?
- To what extent do patients go through the process outlined in our findings *before* the clinic appointments?
- How much do patients undergoing predictive HD testing admit to hope?
- Explore these concepts with the data collected from patients undergoing the deliberation to have BRCA1/2 and pre-natal testing.

The research team

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