

What happens in a clinic appointment for a predictive Huntington's disease (HD) test has been documented in various ways. However, much less is known about the liminal space *between* those sessions.

Our aim was to explore the following questions: 1) how does the decision to have a predictive test for HD impact on patients' lives and 2) what does it feel like for patients to experience this process? This patient group was chosen because the usual pace of decision making does not allow for such detailed scrutiny of this liminal space.

Methods: We recruited 15 patients who were considering predictive testing for HD from four UK regional genetics services. Qualitative data was gathered from patients' reflective diaries to explore the impact of the deliberation process for a predictive HD test and compared with data from clinical appointments. Data was analysed using thematic analysis and illustrated using 'I' poems.

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Findings

In the next few slides, we have some excerpts from the data to illustrate some of our main findings. Firstly, the liminal space.

Liminality is the psychological process of transitioning from one space to the next, so in the context of HD, it could refer to patients transitioning from not knowing their HD status to potentially knowing (Larson, 2014). Whilst patients are in the process of genetic counselling, they are on the threshold separating not knowing from knowing. The liminal space is a space where, potentially, their old narrative no longer applies and their new narrative is unknown (Deary, 2017).

We have two quotes that to illustrate this theme:

"Don't even know what I'm supposed to do as I'm thinking of being tested, but I'm afraid that the results will change my life. If I find out that I am affected, my world will break. I will feel as if I've received some kind of judgement and that I will leave with the knowledge that my life will soon change".

"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."

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Uncertainty is a subtheme of the liminal space theme. It was a very common theme running through the majority of the data and it was clear uncertainty had a big impact on patients' lives. One participant kept audio-recordings as a diary and said:

“One of the strange things for me is that it is exactly a 50/50 chance. One in two. There's no other changes one way or the other, that could influence it. It's probably one of the crappiest odds you could ever come across. Either you have it or you haven't. And there's absolutely no way to tell before, until I get the result.”

The third theme is 'Front and back stage management' referring to the contrasting frontstage data found in clinic appointments and the more revealing and emotional 'backstage' data in diaries. One participant writes:

“I decided to find a more mature idea than suicide by morphine/assisted dying, and relinquish some control there. I decided I could cope with the idea of an assisted directive that says no feeding tube and DNR and I'd die that way. Then I wouldn't go to such an advanced stage as my Nan and my family wouldn't have to suffer, and there'd be no legal trouble for [husband].”

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And lastly, we have a theme, conspicuous in its absence. Almost all participants stated that they were hoping for the best but preparing for the worst. However, their diaries almost exclusively described preparing for the worst. This theme is illustrated here with an I poem, where every instant of I and the word that followed was extracted in order and presented here.

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Discussion

The reflective diaries gave us novel and interesting data and an insight into participants' experiences never seen previously. The use of diaries allowed us to take a participatory approach to answering the research questions, proportionate to the private nature of the diaries and the sometimes-emotive experiences they contained.

Participants descriptions of the liminal space and uncertainty made it appear to be an emotionally uncomfortable place to be. Larson says that “rituals across cultures have the function of moving a person from one status or social circumstance to another” Larson (2014) – could genetic counselling be this 'ritual' that moves a patient from the status of uncertainty to the status of knowing?

It may be possible to develop these explorations of patient deliberation between clinical appointments to inform discussion within clinical appointments.

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