

# The experience of living in the pre-manifest stage of Huntington's disease



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## Background & aims

Little is known regarding how people who are living in the pre-manifest stage of HD cope with the knowledge that they will develop the disease. This paper aims to explore the lived experience of pre-manifest individuals and the longer-term implications of having tested positive for the gene expansion.

## Methods

- Participants: n = (10), aged 18-65, tested positive for the HD gene expansion at least one year prior to the interview, had not been diagnosed with the disease.
- Semi-structured telephone interviews: 40-70 mins
- Qualitative approach (Interpretative Phenomenological Analysis) used

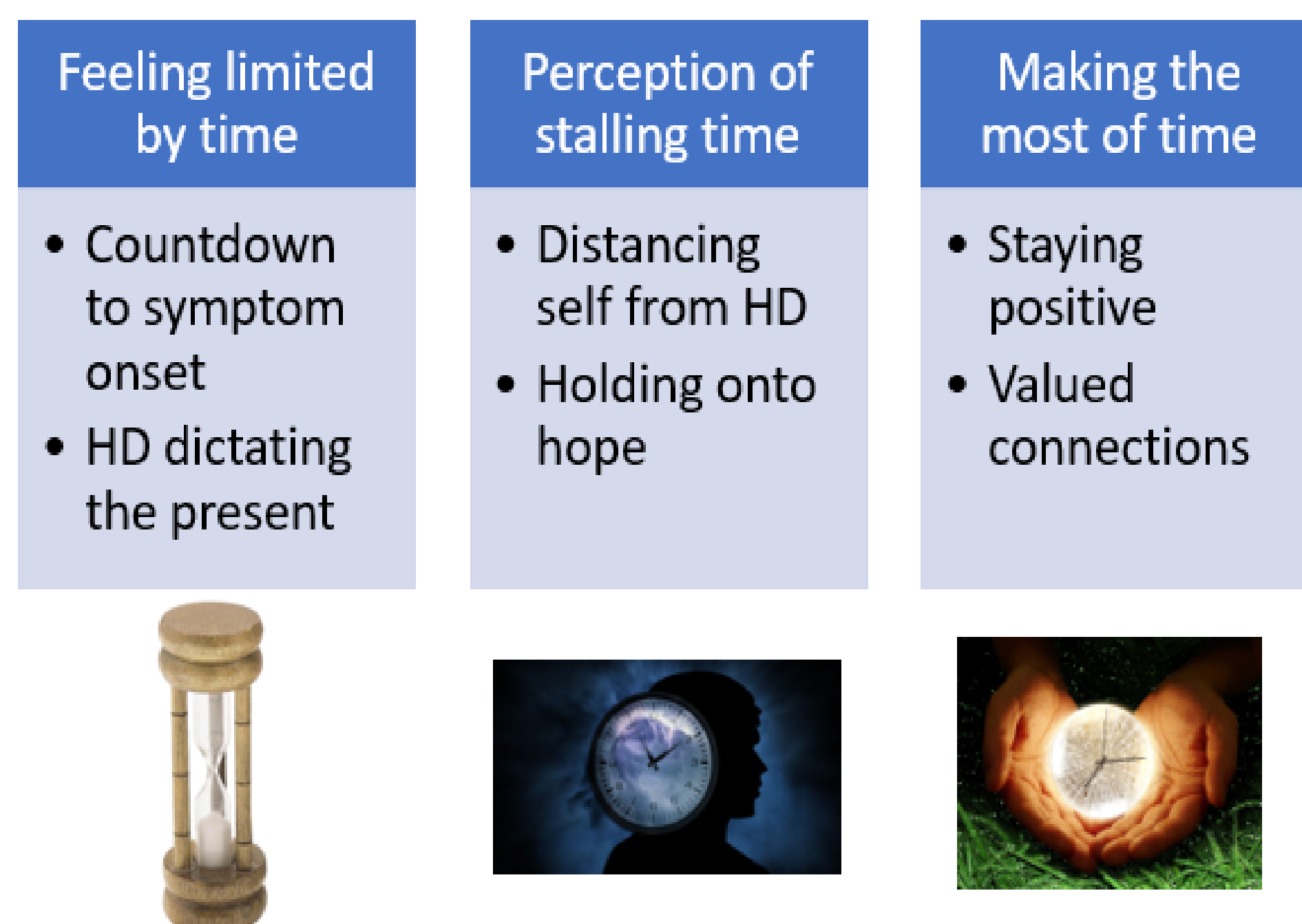
## Results

**Feeling limited by time:** Many participants expressed hyper-vigilance towards potential signs of the disease and were constantly 'symptom watching', such that HD felt to intrude on their day to day lives.

**Perception of stalling time:** In order to manage the unpredictability of living in the pre-manifest stage, participants distanced themselves from the reality of HD. For many individuals, denial of the situation or of approaching symptom onset appeared to be part of a process which enabled them to hold onto hope for a future not defined by HD.

**Making the most of time:** Maintaining a positive outlook allowed individuals to embrace their present and lead a meaningful life. Connecting with friends and family, and discarding negative relationships were an important part of this.

Figure 1: Visual representation of the results



## Discussion

Support should be offered proactively, helping individuals to consider the points in their life when they may experience more distress from a positive test result. Support to help individuals to maintain optimism and live positively in their present appears useful. For participants, this seemed to be about holding onto hope for future medical advances and having gratitude for their symptom free present and the support of family and friends.