

'There is this big gap': The unmet needs of people with advanced Huntington's Disease (HD)

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Background

There has been limited research on the experiences of people with Huntington's Disease (HD) in the advanced stages. We need to better understand these experiences to provide person-tailored holistic care.

Study Objective

To explore the perspectives of people with HD, alongside their families and caregivers.



Portrait of a person with HD

Source: <https://www.yourgenome.org/facts/what-is-huntingtons-disease>

Method

As part of larger study, a participatory group exercise was undertaken with ten participants consisting of people with HD (n=2), families (n=2), caregivers (n=3), nurses (n=3). They were recruited using a convenience sampling approach.

A narrative inquiry was undertaken in a group discussion, followed by telephone and face to face interviews six to eight months after. Reissman's (2008) approach to narrative analysis was used which focused on health care needs.

Findings

The narratives of the participants suggest the need for a common goal of providing quality care that is centred on the person affected with HD. Key storylines were identified based on roles and relationships with people with HD. These included, '*Adapting to the series of losses*', '*Finding inner strength*' and '*Learning through experience*'.

The themes revolve around '*The gaps*' on health care services and lack of practical resources to care for the inexorable progression of HD.

Narrative themes that revolve around the 'Big gap of HD health needs'

Adapting to series of losses

Finding inner strength

Learning through experience

Conclusion

The inquiry illuminated personal attributes and resourcefulness as people with HD, their families and caregivers navigate through different care provisions. Although the participants were optimistic on the clinical developments of HD research, they emphasised the need for awareness and knowledge on a societal and practical level.

There is a need for a coordinated health care system as the complex HD symptoms interjects different health services. Efficient communication among HD services, health and social care organisations can be a step closer to support people with HD in their illness trajectory.

The participatory group exercise is a part of a longitudinal PhD research which explores the illness experience of people with HD, their families and caregivers in different disease stages. The findings contributed to the overall project by giving voice to people with advanced HD, where there is limited research on their subjective experience, problems and needs. To know more about the study, see contact information below.



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