

Patient perspectives

on research themes in advanced Huntington's diseases

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Background

Research in HD is predominantly focused on finding a cure. Less research is designed to improve quality of life. Topaz Huntington Centre Overduin in Katwijk, the Netherlands, has combined care with research on quality of life for many years. Themes of our research projects have been driven by professional therapists, resulting in studies on swallowing difficulties and physiotherapy programs. Three years ago, we composed a Research Agenda to point out the relevant research themes. These included quality of life and self-management. We did not, however, explicitly include the needs and wishes of the HD patients, nor did we evaluate patients' opinions on former research. It is time to improve the Agenda and include plainly the perspectives of the patients at stake.

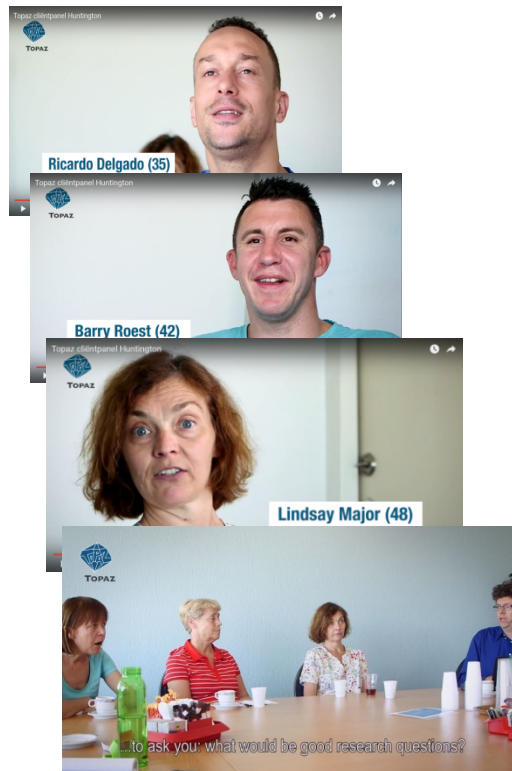
Aim

To include HD patients' opinions, needs and wishes in establishing a new research agenda for our LTC-HD center.

Methods

We invited 6 HD-patients to join a Client panel with a semi-structured agenda. Principal questions were:

1. How have earlier studies helped you to improve your quality of life, and
2. What are the most important themes that we should take up in future studies.



Film

The group session and interviews were filmed to give the participants an even stronger voice. The film has been shown on a conference on good practices in care (*Waarigheid & Trots*), organized by the Dutch department of Healthcare in July 2016 (www.huntingtonplein.nl)

Conclusions

Research themes that are important to HD-patients are not necessarily the same as defined by researchers or professionals. This panel defined social themes as the most important for them. Especially for HD patients, it's essential to include activities and meals in long-term care that fit the wishes of young adults.

Results

All participants concluded that earlier studies on exercise and swallowing did help them in every day life and contributed to a better quality of life. Regarding important new research opportunities, four themes emerged:

1. **Social isolation** - it is very difficult to build new relations: how can this be facilitated?
2. **Daily activities for young adults** – especially for young adults, it's vital to participate in sports and social activities: how to set up a program of activities in the facility fit to the demands of (young) adults?
3. **Control** - if functional independence declines, how do you remain control over your own life? How to live your own life?
4. **Daily meals** - in spite of necessary advises from therapists, how can you pertain meals to be enjoyable and positively challenging? How to cook tasty liquid or grinded meals?

