

E-Health support for HD patients living at home: results of 3 years in practice

Jesseke de Man¹, Lia de Jager¹, Wilco Achterberg^{1,2}

1. Huntington Centre Topaz, Katwijk, The Netherlands 2. Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, The Netherlands

Background

Topaz Huntington Centre Overduin is a 72 bed long-term care facility with specialized daycare and an ambulant support centre for 100 HD-patients. For patients at home additional support and treatment by video-conferencing through e-health technology (EHT) is used since 3 years.



30

25

20

15

10

Nr. of patients

Aim

To describe the results after 3 years of using EHT for support and treatment.

Social worker using video-conferencing

Results

EHT has been used by 55 HD patients at average age of 49 years (27-75) A total of 22 patients have stopped using EHT after mean 419 days. Reasons: admission in a facility (9), cognitive decline (4), refused to use it (3), it was too confronting with the disease (3), died (1), social decline (1).

At this moment the platform is used by 33 patients with an average duration of use of 556 days (11-1326). Support and treatment that are provided:

'It is a lot

better than

calling'

The

platform is

so easy to

use, simple

icons'

- Support from the social worker regarding daily life and support system issues (27 patients), 1/1 or 2 weeks
- Treatment for mood, behavior and acceptance of the disease by the psychologist (12 patients), 1/3 weeks.
- Treatment for swallowing and speech intelligibility by speech therapist (7 patients), 1/2 weeks.

Possibilities of e-health technology

- Support and treatment
- Contact with experts
- •Information about HD
- Support in planning
- Send video messages
- Contact with family
- •Easy access to internet: Huntingtonplein.nl News & meetings Instruction videos Games for cognition



The interface of the e-health platform

I do not have to wait so long; I can ask questions in a short notice'



Scan QR code for a video about video-conferencing

'It is so nice that I can see you'

'It feels like you are at my home'

> 'The frequent contact is so nice'

'Access to expertise without traveling is amazing'

Conclusion

20,30 20,40 40,50 20,60 60,70 70,80

Age of Users

E-health technology can be a sustainable blended care intervention. At our center, we have shown that we can be in intensive contact with our patients who live at home.

It gives HD patients the opportunity to receive treatment at home.

For the organization it is cost-effective because of less travel time.



