

7 years e-Health for HD

Lessons learned

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Background

For 7 years Huntington Center of Expertise Topaz Overduin is using an e-health platform to increase the self-sustainability of HD patients in their home situation. The platform has different functions such as video calling, support and treatment, contact with experts and family, information about HD and has easy access to the internet.

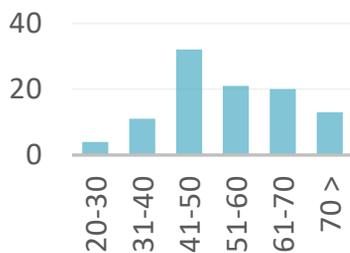
Aim

To gain insights in the use of the platform, the profile of the patient users, their experience and if they indeed experience an increase quality of live and self-sustainability. It represents why certain functions were or were not used. It gives insight in how to further develop the e-health platform.

Methods

Enough data was collected throughout the past seven years to provide an accurate depiction of the experiences of users of the e-platform. Interviews were conducted with platform users including patients and healthcare professionals.

Age patient users



Patient users

- 101 users in 7 years
- 55 stopped using. Reasons to stop: admission of patient (22) lack of interest (14) end of care (8)
- 39 male / 62 female
- 39 living alone / 62 living together

Scan QR code for a video about our e-health platform



Results

- More than one third (46/120) of our patients living at home use the e-health platform. The use of an e-health platform prevents travel time for client, caregiver and therapist, which makes more frequent contact possible.
- Interventions are possible at an earlier stage due to more frequent contact.
- The type of device contributes positively to the independent use of the platform which increases the self-sustainability.
- Video calling is used in particular, other functionalities like email, agenda, less so.
- Outlook, WhatsApp are more integrated in daily live for all users in comparison with the platform.

Conclusions

- The e-health platform contributes to self-sustainability, is embraced by patient users of all ages.
- It is noticeable that some people had resistance to the platform in the first 2 years. It seems like people embrace technology more easily these days.
- It is recommended that healthcare professionals be trained to master the various functionalities.
- In addition, integration of, e.g. email and calendar would be desirable.

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