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Co-creation of an online portal for dialysis patients with low eHealth literacy: effect on adoption

Introduction

The use of information and communication technology in health care, also called eHealth, is an important strategy to create sustainable health care organizations. EHealth can support patients' self-management, for example with patient portals or smart technology to monitor health. Improved self-management can abate the growing care demand, caused by an ageing population.

Patients with *low eHealth literacy (LeHL)* miss competences to seek, find, understand and appraise health information from electronic resources. They are less equipped to adopt eHealth. To overcome disadvantages, it is important to develop interventions that improve access to and use of eHealth for this group of patients. Co-creation with patients is important to tailor interventions to their needs.

This study focuses on dialysis patients with LeHL. Self-management is a major, but challenging component of their treatment. EHealth can support self-management, but low Internet use in patients with kidney disease may limit effectiveness. Less than 1% of existing self-management interventions is co-created, which also seems to reduce effectiveness.

This research aims to 1) explore the eHealth experiences, needs and barriers of dialysis patients with LeHL, 2) discuss eHealth support strategies for this group with health care professionals and 3) assess the impact of co-designed interventions on eHealth adoption and usability.

Methods

To explore eHealth experiences, needs and barriers (Aim 1), we performed two focus group discussions (FGD) (N=3) and in-depth interviews (N=4) with patients with LeHL from two dialysis centers in the Northeastern part of the Netherlands. We assessed eHealth literacy with the eHeals questionnaire. We transcribed and analyzed the data, using the Technology Acceptance Model. The major themes were the starting point for the development of an eHealth intervention.

To discuss eHealth support strategies (Aim 2), we consulted the multidisciplinary team during interviews (N=5) and a workgroup meeting (N=6). We discussed the LeHL patients' experiences, needs and barriers and brainstormed about support strategies. The professionals' input led to the design and content of the first prototype of the eHealth intervention.

To analyze the impact of co-designed interventions (Aim 3) we tested three prototypes, following the principles of design thinking. We tested in four dialysis centers in the same region with 6-8 weeks in-between (N=40). Each prototype was tested by a control group with high (N=7-12) and target group with low (N=6-8) eHealth literacy. Patients were classified as LeHL by asking them about computer use and with a shortened form of the eHeals. Some participants tested all prototypes to reflect on improvements. Half of the approached re-testers with LeHL (N=4) were lost at follow-up. They were not motivated for a second test. All groups navigated the prototypes, following a scenario. A computer program measured navigation behavior. Talking-out-loud was used to assess perceived usability and satisfaction. An eHealth adoption questionnaire was used to validate results. Analyzed data were used to re-design each following prototype.

Results

Characteristics

LeHL patients had a mean age of 70 and all followed low or middle education. They visited in center dialysis three times a week. The health care professionals were a good representation of the multidisciplinary team.

eHealth experiences, needs and barriers

Main barriers for eHealth adoption were a lack of computer knowledge, skills and experience. Participants also reported resistance against digitalization, because they believe it reduces personal contact and impacts quality of life, for example when shops close. Fear for privacy issues and errors played a role in the intention to adopt eHealth. High-frequent contact with professionals further diminishes the need for eHealth. Patients reported that an easy design and support of others are important facilitators. Main content needs are information on lab values, diet and medication.

Finding an eHealth strategy

Professionals validated the suggested content by the patients. They suggested an easy-to-use prototype patient portal, with a personal patient story and realistic medical information, to support patients with LeHL. During use, patients should get hints and rewards to heighten entertainment.

Co-development and analysis

Patients with LeHL believed the content of the first prototype was useful, but too difficult. The computer program showed that patients lack basal skills to navigate. They struggled to open videos and read written content due to language barriers or impatience. The questionnaires showed a trend that patients with LeHL were more negative about their skills and knowledge after use.

In the second prototype information was simplified and personalized. The design was enriched with colors and symbols. LeHL patients showed improved navigation and expressed higher satisfaction with the design and comprehensibility, especially of the lab values. Questionnaires showed that participants were, after use, more positive about usefulness and their competences. Although, LeHL patients were not always convinced about the need to use eHealth in the future. The analyzed results of the third prototype are expected in one month.

Conclusions and discussion

Many dialysis patients are low eHealth literate. They miss competences to adopt eHealth and have negative thoughts about digitalization. If possible, they prefer face-to-face support. Co-creation helps to develop comprehensible and easy-to use eHealth solutions for patients with LeHL, which can increase belief in personal competences.

Health care organizations should improve support of patients with LeHL in an evolving digital world. Developers should improve the usability of patient portals, since this can facilitate eHealth adoption by empowering the patients' belief in personal competences. Face-to-face contact offers another possible strategy. When professionals succeed to explain benefits and incorporate eHealth in consultations, patients are more willing to use it. Organizations should also reach out to the patients' relatives, since they often support Internet use.

This research also indicates the importance of co-creation. The first prototype led to a negative experience and a reduced belief in personal competences. The loss-to-follow-up in the group with LeHL illustrates that non-tailored eHealth solutions can cause a direct loss of users. Co-creation and the relation to adoption needs further research and implementation in eHealth development.