Alzheimer's & Dementia: Translational Research & Clinical Interventions 4 (2018) 141-149

Featured Article

Wishes and preferences for an online lifestyle program for brain health—A mixed methods study

Linda M. P. Wesselman[a,*], Ann-Katrin Schild[b], Nina Coll-Padros[c], Wieke E. van der Borg[d], Judith H. P. Meurs[a], Astrid M. Hooghiemstra[a], Rosalinde E. R. Slot[a], Lena Sannemann[b], Lorena Rami[c], José Luis Molinuevo[c,e], Femke H. Bouwman[a], Frank Jessen[b,f], Wiesje M. van der Flier[a,g], Sietske A. M. Sikkes[a,g], on behalf of the Euro-SCD working group

[a]*Alzheimer Center, Department of Neurology, VU University Medical Center, Amsterdam Neuroscience, Amsterdam, the Netherlands*
[b]*Medical Faculty, Department of Psychiatry, University Hospital Cologne, Cologne, Germany*
[c]*Alzheimer's Disease and Other Cognitive Disorders Unit, Hospital Clínic, Institut d'Investigacions Biomèdiques August Pi i Sunyer (IDIBAPS), Barcelona, Spain*
[d]*Department of Medical Humanities, VU University Medical Center/EMGO+, Amsterdam, the Netherlands*
[e]*Barcelona βeta Brain Research Center, Pasqual Maragall Foundation, Barcelona, Spain*
[f]*German Center for Neurodegenerative Disorders (DZNE), Bonn-Cologne, Germany*
[g]*Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, the Netherlands*

Abstract

Introduction: Individuals with subjective cognitive decline (SCD) are at increased risk of Alzheimer's disease and could benefit from a prevention strategy targeting lifestyle factors. Making a program available through the Internet gives a widespread reach at low cost, but suboptimal adherence is a major threat to effectiveness. As a first step in developing an online lifestyle program (OLP), we aimed to identify factors that are barriers and/or facilitators for the use of an OLP in individuals with SCD in three European countries.

Methods: As part of the Euro-SCD project, SCD subjects were recruited at memory clinics in the Netherlands, Germany, and Spain. We combined quantitative and qualitative methods, using a mixed methods approach. We conducted an online 18-item survey on the preferences of SCD patients for an OLP (N = 238). In addition, we held semi-structured interviews (N = 22) to gain in-depth understanding of factors acting as a facilitator and/or barrier for intended use of an OLP. Audio recordings were transcribed verbatim. Content analysis was performed.

Results: One hundred seventy-six individuals completed the survey (response rate 74%). Almost all participants regularly use the Internet (97%). Participants reported trustworthiness (93%), user-friendliness (91%), and up-to-date information (88%) as main facilitators, whereas having contact with other users (26%), needing an account (21%), and assignments (16%) were reported as barriers. Barriers differed slightly between countries, but facilitators were largely similar. In-depth interviews revealed that both program characteristics (e.g., trustworthiness, user-friendliness, and personalization) and personal factors (e.g., expectancy to receive negative feedback) are likely to influence the intended use of an OLP.

Discussion: Involving users provided in-depth understanding of factors associated with the intended use of an OLP for brain health. Both program characteristics and personal factors are likely to influence the use of an OLP. Based on this input from the end-users, we will develop an OLP for individuals with SCD.

*Corresponding author. Tel.: +31204440816; Fax: +31204448529.
E-mail address: l.wesselman@vumc.nl

https://doi.org/10.1016/j.trci.2018.03.003

Keywords: Prevention; Alzheimer's disease; Dementia; Subjective cognitive decline; Online lifestyle program; E-health; Brain health; Cognition; User participation; Co-creation; Mixed methods

1. Background

The number of people with Alzheimer's disease (AD) will dramatically increase in the coming 30 years [1]. Unfortunately, there is no successful therapeutic intervention for AD yet [2]. However, there is a large window for preventive strategies because brain changes related to AD start decades before the clinical onset of the disease [3]. Former studies have suggested that roughly 30% of the incidence of dementia is attributable to a combination of modifiable risk factors [4–6]. This emphasizes the potential for lifestyle intervention as a strategy to reduce the incidence of AD or delay its onset.

The Internet is a suitable medium to make interventions available for a large audience at a low cost [7]. Online strategies have been found to be effective in changing lifestyle behavior [8,9]. Recently, a number of preventative strategies against cognitive decline were developed including online components (e.g., [10,11]). However, online interventions have difficulty achieving good adherence rates [12–14]. A recent analysis of adherence to the FINGER study and MAPT trials showed low simultaneous adherence to all components with lowest adherence being related to more intensive and unsupervised parts of the intervention [15]. It is unknown whether cultural difference between countries might play a role in differences in adherence. Many interventions could benefit from a more participant-centered design. In case of low adherence, it is possible that end-users were insufficiently engaged in the process of development. Involving users throughout development in a process of co-creation has a positive effect on user satisfaction and fitting user preferences [16–22]. The investigation of preferences, barriers, and facilitators that influence the use of a lifestyle intervention is more common in other clinical research fields (e.g., [23,24]). However, only a few projects specifically investigated these factors at the beginning of the development process (e.g., [6]). Preferences of individuals with cognitive complaints for a lifestyle intervention for brain health have not yet been investigated.

In this study, we focus on individuals who report cognitive decline, while their scores on cognitive tests are normal. Former studies have shown that these individuals with so called "subjective cognitive decline" (SCD) are at increased risk of dementia [23–26]. Furthermore, individuals with SCD are likely to be highly interested in brain health. With the ultimate aim to develop an online lifestyle program (OLP) tailored for individuals with SCD (Fig. 1: project overview), we performed a mixed methods study to identify factors that would act as barrier or facilitator in the usage of an OLP among SCD subjects in three European countries. We specifically aimed to identify factors important to self-guided programs.

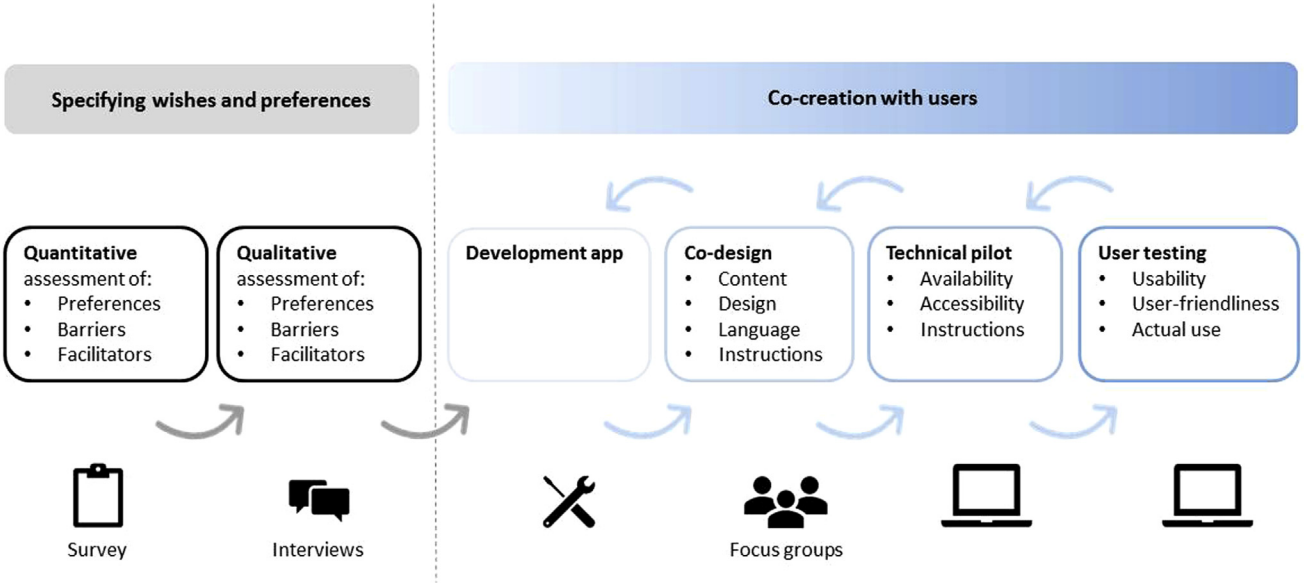

Fig. 1. Project overview. This figure shows the developmental steps of an online lifestyle program for brain health within the EuroSCD project. First, wishes and preferences were investigated using a mixed methods approach, which is described in the present study. This phase included a survey study and interviews. Second, in co-creation with the users, an iterative process of development and evaluation will be conducted, with the ultimate aim to develop an online lifestyle program fitting the preferences of individuals with subjective cognitive decline. Abbreviation: SCD, subjective cognitive decline.