PO2-417 Developing a web-based platform for people living with dementia and their caregivers: a user-participatory study

Rosie Dunn[1,2], Paraskevi Zafeiridi[1,2], Emma Wolverson[2], Kevin Paulson[1] Caroline White[3]

[1]School of Engineering, University of Hull, United Kingdom
[2]Department of Psychological Health and Wellbeing, University of Hull, United Kingdom
[3]School of Health and Social Work, University of Hull, United Kingdom

Background

Due to the increasing number of people living with dementia (PLWD), research has explored low cost-effective interventions, such as web-based interventions, to address the needs of PLWD and their caregivers (Blom et al., 2015; Span et al., 2015). Recent literature supports the need of involving end users, such as PLWD, caregivers and healthcare professionals in the development of web based interventions (Span et al, 2013).

CAREGIVERSPRO-MMD is a European project developing a platform designed for PLWD or Mild Cognitive Impairment (MCI), caregivers and healthcare professionals. It involves different functions such as; educational material to learn about dementia and psychological wellbeing, online forums, social networking, information about local resources and medication and appointment reminders.

The present study is ongoing and is conducted to collect PLWD, caregivers and healthcare professionals' opinions and insight into the development of a web-based platform.

Method

Design
A qualitative, constructivist, user-participatory design.

Participants
- PLWD (n=16, mean age=78.68 yrs, $SD=5.34$ yrs, age range=70-89, 9 males)
- Caregivers (n=20, mean age=55.66 yrs, $SD=13.64$ yrs, age range=29–89 yrs, 18 females)
- Healthcare professionals (n=46)

Procedure
In the first study, volunteers from Italy, Spain, France and the United Kingdom participated in focus groups or individual interviews, where they were shown demonstration videos and had the opportunity to practice using the platform. In the current study participants will have the opportunity to practice using the updated version of the platform. Similar to the first study, participants opinions about the platform will be collected via focus groups or individual interviews.

http://uk.complex.com/pop-culture/2013/10/old-people-using-computers/

Results

PACT (People, Activities, Context and Technology) analysis was used so that designers become aware of the participant characteristics, actions performed in the platform, context of use and various existing technologies. In addition, qualitative analysis was used to explore participant's insights about the platform. The results from PACT analysis of the first study are illustrated in Table 1.

People	Activities	Context	Technology
PLWD/MCI: people with mild or moderate dementia, or mild cognitive impairment	Interface design adaptation, cognitive training activities, educational material	Home environments No time pressure Barriers accessing internet and ICT devices Help from caregivers	Icons and pictures are preferred
Caregivers: formal or informal carers of PLWD or MCI	Educational material about dementia and caregiving, personalized information, sharing experiences with other caregivers and professionals	Easy access to internet connection Support needed to learn how to use the platform	Video/tutorials for instructions
Professionals working with PLWD/MCI and their caregivers	Security settings and data protection, setting up tailored interventions	To access the platform from their workplaces Easy access to internet connection Low level of support needed	Manual input of medical information by professionals

Table 1. PACT analysis for all user groups

The focus group and semi-structured interviews revealed that most of PLWD (70%) had no previous experience using ICT devices and accessing the web. On the other hand, the majority of caregivers (80%) had experience using ICT devices. Other findings from this first study showed that PLWD would be interested in cognitive games to train their skills, such as their memory. Caregivers had high expectations about improving their social contacts through the platform. Professionals believed that medical issues can be better addressed through the platform than in person. Caregivers and professionals were concerned about the privacy of users' data. The results from the current study are expected to show an improvement of the platform in its security and privacy settings for the data of users.

Discussion

Overall, the results of the first study indicated the need of PLWD or MCI and their caregivers to receive support for learning how to use ICT devices and CAREGIVERSPRO-MMD platform. There was a clear need to improve the interface of the platform and adopt it to the different user groups (PLWD, caregivers, professionals).

The major concern of users was about the security and privacy of their data and thus, this was taken into account for the development of the platform. The findings from the ongoing study are expected to show that this privacy issue was successfully resolved in the updated version of the platform.

References
Blom, M. M., Zarit, S. H., Groot Zwaaftink, R. B. M., Cuijpers, P., & Pot, A. M. (2015). Effectiveness of an internet intervention for family caregivers of people with dementia: Results of a randomized controlled trial. PLoS ONE 10(2): e0116622.
Span, M., Hettinga, M., Vernooij-Dassen, M., Eefsting, J., & Smits, C. (2013). Involving people with dementia in the development of supportive IT applications: A systematic review. Ageing Research Reviews, 12(2), 535–551.
Span, M., Smits, C., Jukema, J., de Groen-van Leontine, Janssen, R., Vernooij-Dassen, M., Eefsting, J., & Hettinga, M. (2015). An interactive web tool for facilitating shared decision-making in dementia-care networks: A field study. Frontiers in Aging Neuroscience, 7(July), 1–12.

R.J.Dunn@hull.ac.uk