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Evaluation of benefits of the CAREGIVERSPRO-MMD platform giving support and assistance to people living with dementia and their primary caregiver

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Background and study aims

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities, including memory loss and difficulties with thinking, problem-solving or language. There are 46.8 million people living with some form of dementia worldwide for which there is currently no treatment or effective strategy that can halt or reverse their decline. As Europe's population is aging, and longevity is the main risk factor for developing dementia, long-term care for older citizens will represent an increasing financial cost for society (1). There are currently 19 million people living with dementia in Europe, and this figure is expected to reach 31.5 million by 2050. To manage this transition, health policies of the EU and its member states are focused on enhancing elderly people's longevity and preventing their dependency. This has the double aim of increasing their quality of life while reducing costs and increasing the effectiveness of healthcare (2). That is why this study (prospective, interventional, randomized, multicenter, longitudinal and parallel clinical trial) aims to test the web platform " CAREGIVERSPRO-MMD" (3), which is accessible from computers, phones and tablets, and designed specifically for caregivers and people living with mild cognitive impairment or mild to moderate dementia. It provides services to improve the quality of life of those living with cognitive impairment or dementia as well as that of their caregivers, thus supporting them to live in the community for as long as possible.

Who can participate?

Patients aged 50 and over living with mild cognitive impairment or (mild to moderate) dementia and their caregivers, aged 18 and over

Intervention

Dyads (people living with mild cognitive impairment or dementia (mild to moderate) and their primary caregivers) are randomised into two groups:

- 1. A group using the CAREGIVERSPRO-MMD platform
- 2. A control group without access to the platform

What does the study involve?

Participants are randomly allocated into two groups. One group is given access to the platform and the other group is not. During the following 18 months, the following aspects are assessed: the patient's health (general health, brain functioning, activities of daily living, quality of life, adherence to drug treatment and other illnesses), social aspects (cohesion, social support, success in relationships, self-esteem, purpose and optimism), and economic aspects (cost-effectiveness of the use of the platform) and the degree of satisfaction and usability of the platform

Ethics approval

Ethics board Fundació La Unió, 07/12/2016, ref: CEIC 16/87







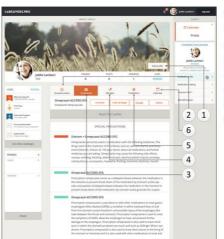






What are the possible benefits and risks of participating?

Using the CAREGIVERSPRO-MMD platform is expected to improve the quality of life of people living with mild cognitive impairment or dementia, and reduce the level of burden experienced by the caregiver. There is no risk because CAREGIVERSPRO-MMD is a platform based on a social network for the monitoring and support of its users. Therefore, no risk to the user's health is expected.



CAREGIVERSPRO-MMD

- 1) General information ("edit profile")
- 2) Questionnaires
- 3) Treatments
- 4) Allergies
- 5) Conditions
- 6) Events ("calendar")

Study hypothesis

The dyad (formed by the person living with mild cognitive impairment or mild to moderate dementia and their primary caregiver) and the social and health circle which is structured around it (family, friends, other dyads, health personnel...), generates a lot of information regarding social and health concerns to improve living conditions and assessing the progression of the dyad. The existence of a platform based on Information and Communications Technology (ICT), capable of channelling all information generated and encouraging the search for solutions to specific problems, equipped with sensitive health monitoring tools and the possibility of putting all the different people living with mild cognitive impairment or dementia (mild to moderate) into direct contact; both the dyad as well as medical professionals or other dyads in the same situation; will improve the quality of care, control and monitoring of illness, resulting at the same time in a better diagnosis and an improvement in the subjective quality of life and health of its members.

ISRCTN

www.isrctn.com/ISRCTN15654731

Trial website

www.caregiversprommd-project.eu







(1) Kawas, C. H. & Corrada, M. M. Alzheimer's and dementia in the oldest-old: a century of challenges. Curr. Alzheimer Res. 3, 411–419 (2006). (2) Dröes, R. M. et al. Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. Aging Ment.

(3) CAREGIVERSPRO-MMD, Project. Pilot Operation Manual. (2016). Available at: http://caregiversprommd-project.eu/wp-content/uploads/Pilot-Operation-Manual.pdf.

