

ORAL SESSION 8: EXPERIENCED HEALTH AND (SELF) RESPECT

How do people living with subjective cognitive impairments want to get support in resilience?

S. Suijkerbuijk, L. Abdel Alim, R. Bevilacqua, E. Felici, L. Rossi, S. Casaccia, L. Scalise, A. Pollini, S. Swaminathan, H.H. Nap, A. Astell

Suijkerbuijk et al. (2020). *Gerontechnology* 19(suppl); <https://doi.org/10.4017/gt.2020.19.s.69949>

Worldwide it is estimated that there is one new case of dementia, every three seconds (Alzheimer's Disease International, n.d.). There are currently approximately 50 million people living with dementia, and this number is predicted to reach 131,5 million in 2050. Mild Cognitive Impairment (MCI) is another age-related condition, in which an individual has mild but measurable changes in cognitive abilities that are greater than would be expected for their age. There is good evidence that a healthy lifestyle and cognitive stimulation can reduce both the risk of developing dementia and its progression (Barnes & Yaffe, 2011; Mangialasche et al., 2012). As we wait for disease-modifying therapies for dementia, there is an urgency for new strategies to appraise the preferences, feelings and expectations of people who experience cognitive impairments, and to leverage and maximize their residual skills. Despite the large amount of research on how to exploit Information and Communication Technology (ICT) to support self-management of chronic diseases, there is a lack of clear direction when it comes to self-management by older People with Cognitive Impairment (PwCI). This is due to a persisting bias of not considering people with Cognitive Impairment as capable of participating in the care sector. However, research shows that people with cognitive impairments, such as dementia, can have an active role in development of supportive technologies (Suijkerbuijk et al., 2019). Within the Resilien-T project (Resilien-T, n.d.) the project team adopted a human-centered and participatory design perspective toward developing new features on an existing tablet-based platform. Specific objectives of the project are: 1. To develop an open, modular, adaptable platform to provide self-management and coaching services to PwMCI, integrating informal and professional caregivers as necessary, to be used either autonomously or in conjunction with on market systems for lifestyle monitoring or wearable devices; 2. To develop evidence-based applications (apps) to support self-management by PwMCI, covering the areas of nutrition, physical social and cognitive activities. From interviews (total of 25) in three countries to multiple participatory workshops (total of 10), the project pre-design and generative phase was steered by direct interaction with primary and secondary end-users. The concept of 'active living' was explored within these workshops. Furthermore, the involvement of end-users results in the insight that different people desire different ways of motivational support in the Resilien-T platform. The concept formulation steered the iterative development of a dynamic user-sensitive interface that will be researched in a large trial over 12 months with 150 PwMCI and 150 caregivers in Italy, Netherlands, Switzerland and Canada.

References

- Alzheimer's Disease International. (n.d.). Dementia Statistics. Retrieved from <https://www.alz.co.uk/research/statistics>
- Barnes, D.E. & Yaffe, K. (2011). The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol*, 10(9), 819-828. [https://doi.org/10.1016/s1474-4422\(11\)70072-2](https://doi.org/10.1016/s1474-4422(11)70072-2)
- Mangialasche, F., Kivipelto, M., Solomon, A. & Fratiglioni, L. (2012). Dementia prevention: current epidemiological evidence and future perspective. *Alzheimer's Research & Therapy*, 4(1). <https://doi.org/10.1186/alzrt104>
- Resilien-T. (n.d.). AAL-Call-2018 – Smart Solutions for Ageing Well, RESILIEN-T project. Retrieved from <https://resilien-t.eu>
- Suijkerbuijk, S., Nap, H.H., Cornelisse, L., De Kort, Y.A.W., IJsselsteijn, W. & Minkman, M.M.N. (2019). Active involvement of people with dementia: A systematic review of studies developing supportive technologies. *Journal of Alzheimer's Disease*, 69(4), 1041–1065. <https://doi.org/10.3233/JAD-190050>

Keywords: cognitive impairments; participatory design; supportive technology; resilience

Address: IRCCS INRCA, Via Santa Margherita 5, 60129 Ancona, Italy

Email: r.bevilacqua@inrca.it