The Technology-Enhanced Ability Continuum-of-Care Home Program for People with Cognitive Disorders: Concept Design and Scenario of Use

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Abstract. Alzheimer's disease (AD) has been identified as one of the 25 top causes of years lived with disability. Currently, no pharmacological treatment can prevent, slow down, or stop the course of this disease. From the clinical and health management perspectives, Mild Cognitive Impairment – a condition representing a risk factor for the development of dementia - and early stages of AD are the most interesting conditions for interventions aimed at delaying further decline. Telemonitoring and telerehabilitation home-based services have been advocated to provide manifold benefits for people with cognitive disorders. In this paper, we will describe the concept vision enlightening Ability, a technology-enhanced continuity-of-care home program for people with cognitive disorders. After describing the platform architecture, we will present a use case showing how it benefits people with cognitive disorders and both formal and informal caregivers by generating intertwining support in the process of care, enhancing well-being, health conditions, and inclusion.

Keywords: Telerehabilitation · Cognitive disorders · Alzheimer's disease Dementia · Cognitive rehabilitation

P. Cipresso et al. (Eds.): MindCare 2018, LNICST 253, pp. 64–73, 2018.
https://doi.org/10.1007/978-3-030-01093-5_9

1 Introduction

Currently, about one-eighth of life expectancy worldwide is associated with disability [1]. An epidemiological shift was detected between 1990 and 2013, showing increasing numbers for non-communicable diseases and, at the same time, decreasing rates for communicable disorders. Among non-communicable disorders, Alzheimer's disease (AD) has been identified among the 25 top causes of years lived with disability [2].

AD is the most common form of dementia, being a progressive neurodegenerative condition accounting for up to 60% of all dementia cases [3]. From the clinical and health management point of view, Mild Cognitive Impairment (MCI) – a condition representing a risk factor for the development of dementia - and early stages of AD are the most interesting target for interventions aimed at preventing or delaying further decline [4]. So far, no pharmacological therapy is available to prevent the potential conversion from an MCI to an AD condition, or to affect the course of AD.

Nevertheless, different types of non-pharmacological interventions have been conceived to meet this challenge and an increasing body of results shows that cognitive functions of people with mild to moderate dementia benefit from cognitive stimulation programs, over and above any medication effects [5]. However, to consolidate this evidence, the adoption of robust experimental designs and validated and reliable measures of efficacy on both cognitive and non-cognitive (i.e., Quality of Life; QoL) outcomes is still crucial [6]. Furthermore, among non-pharmacological interventions, using technology to provide a range of home-based services has currently gained importance [7]. Several benefits of these long-distance monitoring and rehabilitation services have been highlighted. For instance, these services provide equitable access to local sanitary systems for individuals who are geographically remote and/or with physical disabilities [8], remote therapeutic interventions and monitoring of progress, lower costs, and support of the person with dementia-caregiver dyads at home [9, 10]. Indeed, computer-based interventions are often cited in many literature reviews on cognitive interventions, [5, 11, 12] because of the opportunities they provide in terms of fine-grained adjustments and individual tailoring of intensity and duration of cognitive rehabilitation/stimulation programs. Nonetheless, the lack of familiarity of older adults with technologies and computers is often raised as a potential obstacle for their adoption [13].

Within this scenario, the technology-enhanced Ability continuity-of-care home program for people with cognitive disorders has recently been devised within the Ability Project, funded within the Smart Cities and Communities Funding Program (MIUR-POR LOMBARDY; AXIS 1; POR FESR 2007–2013). The Ability project Consortium included industries and SMEs, Research institutions, and PAs, which received an overall funding of 4,08 MI euros.

In this paper we will first focus on the architecture of the platform, designed and developed to enable the continuity-of-care Ability program. We will then present a use case highlighting how it benefits both people with cognitive disorders and formal and informal caregivers by the generation of continuous and intertwining support in the process of care.

2 The Technology-Enhanced Ability Continuity-of-Care Home Program for People with Cognitive Disorders: Platform Architecture and Use Scenario

The technology-enhanced Ability continuity-of-care home program targeted the design, development and validation of a smart care environment. The aim of such program was to foster inclusion, well-being, and health conditions of people with cognitive disorders, providing continuous support to their caregivers at the same time.

The vision of the Ability program was to develop and test a Personal Smart Care Community enabling innovative trajectories for dementia care. Such Community puts the patient at the core of an intertwining treatment and support from both formal (e.g. physicians) and informal (e.g. near relatives) caregivers while moving from hospital-based to home-based care.

To reach this aim, the designed and developed Ability platform represents a tool to monitor vital parameters remotely, and to deliver motor and cognitive rehabilitation activities.

The system of the Ability platform is based on the Telbios Connect, a telemonitoring platform for chronic patients already existing prior to the design and development of the Ability continuity-of-care program. The architecture of the Telbios Connect platform, with the Ability vertical application integrated in it, is shown in Fig. 1.

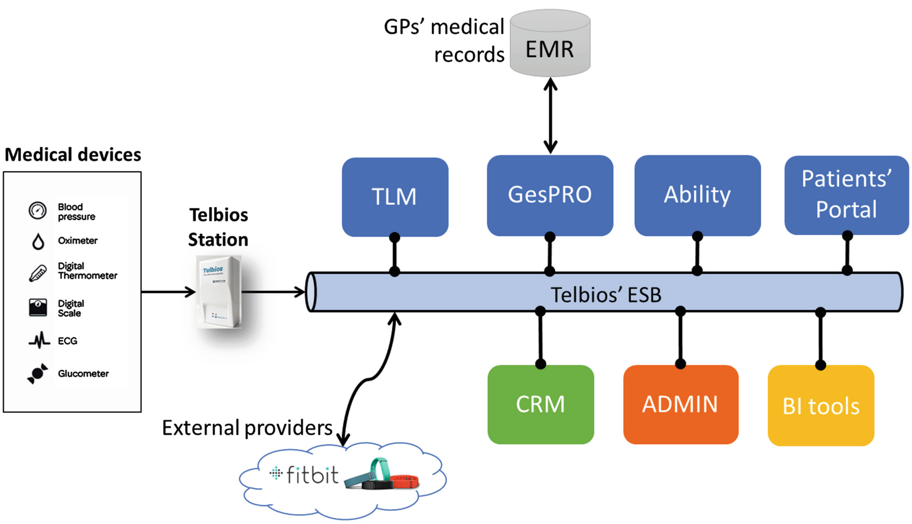

Fig. 1. The architecture of the Telbios Connect platform with the Ability vertical application integrated.

The Telbios Connect platform is centered on an Enterprise Service Bus (ESB) that connects all proprietary and third party applications. Besides administrative (ADMIN) and Business Intelligence Tools (BI Tools), the platform provides a Customer

Relationship Management (CRM) tool, which the Telbios Service Center uses to manage users in the different services. The ESB also allows the integration and exchange of data with external services (e.g., Fitbit APIs) or hardware, such as the Telbios Station, a residential gateway that connects Bluetooth self-monitoring devices.

On top of this core infrastructure, vertical applications can be developed in order to benefit from the exchange of information. Among these, for example, the GesPRO allows General Practitioners (GPs) to manage chronic patients, prescribing yearly care plans and monitoring their statuses. The telemonitoring application (TLM) allows the collection of vital parameters such as weight, heart rate, ECGs, SpO2, blood pressure and blood glucose, based on a Telemonitoring Plan (TP) defined by a clinician. Moreover, the platform can analyze the data from vital parameters in real time and activate specific protocols of escalation on nurses or physicians, depending on the severity of the identified condition of the patient.

During the design and development of the Ability continuity-of-care home program, the platform was extended to include also: (a) data coming from commercial actigraphy devices (i.e., the Fitbit tracker), hosting motor activity and sleep behavior data; (b) motor and cognitive rehabilitation contents, developed ad-hoc for the program or hosted on third party platforms, and a defined interface for results exchange.

Using Telbios Connect as a starting point, the Ability application was then built around the concept of Individual Rehabilitation Plan (IRP). In the Ability continuity-of-care program, the IRP includes cognitive rehabilitation activities (a library of 546 tablet-based digital activities developed ad hoc for the program to reinforce multiple cognitive domains), motor activities (both adapted and light aerobic exercises) and behavioral suggestions (regarding sleeping times, daily naps, etc.), in addition to the monitoring of specific vital parameters already integrated in the TLM module.

This way, the Ability continuum-of-care platform works with a twofold scenario of use.

On the one hand, through the physician's portal, healthcare professionals are able to define the IRP according to individual clinical conditions of People With Dementia (PWD). They can set up the type and dose of motor and cognitive rehabilitation activities (e.g., establishing the sequential framing of cognitive activities reinforcing multiple domains of cognitive function, or defining the alternation between activity periods and pause periods), and the frequency of measurement of vital parameters. Moreover, they can support the rehabilitation process remotely, monitoring the progresses and, if needed, adapting the IRP to provide a day-by-day tailored intervention. They can also check the compliance with the at-home rehabilitation plan, contacting PWD and caregivers when appropriate, in order to adjust the intervention: for example, to improve motivation and to foster engagement in the care process.

On the other hand, through the user's portal, PWD and caregivers can access the IRP at home through a tablet application. On each day of intervention, after opening the user-friendly dashboard, PWD can see the cognitive and motor rehabilitation activities planned by the clinician for that day. A message on the dashboard appears more than once a week to recall them to measure the vital parameters, according to physician's recommendations. In the case of the Ability program, no tablet-based recalls were included regarding the Fitbit tracker, since participants were required to wear it continuously (24 h) throughout the intervention, except for very short interruptions to recharge it.

This way, PWD can take an active role in following the IRP at home with the prescribed sequence and timing of activities. At the same time, caregivers can monitor PWD's progresses, with the opportunity to be empowered with their autonomy in supporting the care process.

Based on the Ability platform and the scenario of use just outlined, it is herein described a use case that highlights how Carla, a person with cognitive disorders, succeeded in accomplishing the rehabilitation activities devised for his condition through the Ability continuum-of-care home program.

2.1 Heading the Target at the Right Pace: A Use Case of the Ability Continuum-of-Care Home Program

Carla is a 70-year-old scholar in Russian history still occasionally writing short papers and essays. In the last few years, she realized she had difficulties with her memory: she often forgot where she had left her home keys, or, if asked what she had eaten at lunch, she could no longer recollect it, even just few hours later. While she still was independent and autonomous in carrying out activities of daily living, with only minor difficulties in cooking a meal or arranging her outfit accurately, sleep disorders started to become more frequent. And writing her essays, especially in the morning as she was used to, turned out to be more demanding. Her husband was first puzzled, then worried, and, as these difficulties showed more and more often, he felt stressed for being unable to cope with them. After undergoing an extensive neuropsychological assessment and a clinical neurological evaluation, together with laboratory and imaging examinations, Carla was framed in the Mild Cognitive Impairment condition, a preclinical condition representing a risk factor for the development of AD. In view of this, clinicians also told Carla that several protective factors had been identified that may delay the onset of clinical AD. The multifactorial nature of AD indeed suggests that multicomponent interventions pointing at several risk factors simultaneously can generate optimal preventive effects. Concerning lifestyle-related risks, Carla was recommended to keep targeting a lifetime cognitive activity, combined with physical exercise, social stimulation, and appropriate nutritional guidance. She was therefore advised to accomplish several tasks according to the usual care protocol devised for outpatients of the Memory Clinic in the same preclinical condition. Regarding cognitive functioning, she received a workbook comprising paper and pencil cognitive activities to be performed at home for five days a week. She was also recommended to carry out a light aerobic motor activity every day (e.g., walking outdoor for about half an hour), to monitor blood pressure at least twice a week, and to keep her nutritional habits under control, shifting them towards Mediterranean diet options. She was then given a follow-up appointment after six months with the several professionals involved (physician, therapist, neuropsychologist). While being compliant with the program's task and recommendations in the first weeks, in the long run Carla started to feel less motivated in carrying them out. One day the weather was miserable and lying on the sofa reading with her cats was far more attracting to her than walking outdoors. Moreover, she felt that the progression of difficulty of cognitive activities (set independently of her cognitive resources) was often not in line with what she could (or could not) do. So, when activities were too easy for her, she sometimes performed also those prescribed for several days to come, while, if she perceived them too difficult, she simply gave them up. She also often forgot to monitor blood pressure. Timing and pacing of the several activities, and especially of physical exercises, were totally disrupted and, by the end of the second month, she felt disappointed and frustrated with the program, which she perceived as an objective she was virtually unable to pursue. At the six-month follow up, after clinical re-evaluation and neuropsychological assessments, a progression of impairment was detected, although she was still autonomous in her functional daily activities. In the meantime, among other front-edge neurorehabilitation research activities, the Memory Clinic was involved in a research project – the Ability project - envisioning a technology-enhanced concept of care for PWD, enabling smart continuity-of-care trajectories based on telemonitoring and telerehabilitation. About six months later, Carla was then invited at the Memory Clinic to join the Ability program for six consecutive weeks. At the beginning she was a bit nervous: she was not confident at all with tablets, and the kind of watch (the Fitbit tracker) she was asked to wear 24H seemed a bit too innovative and juvenile, compared to her feminine and traditional one. Anyway, together with her husband, she participated in the learning-by-doing training session of the telemonitoring devices and of the tablet activities, during which they became familiar with the dashboard that every day would deliver the cognitive, motor and monitoring activities that clinicians had set for her Individual Rehabilitation Plan. They went home with the Ability kit, that included: (a) the tablet for the delivery of the IRP, the memos for the monitoring of vital parameters and nutritional suggestions; (b) the Fitbit® Charge, to track motor and sleep activity; (c) a sphygmomanometer for the detection of blood pressure; (d) a pulse oximeter for the measurement of oxygen blood level and heart rate; (e) a scale for the detection of body weight; (f) the Telbios Station to send data collected from all the technological devices to the Ability platform.

During the six-week Ability program, Carla felt supported in her everyday rehabilitation tasks: the dashboard recalled her when to monitor vital parameters, while progression rules for increasing difficulty in cognitive activities fitted her resources in a way she perceived as well balanced. Watching the videos of exercises of adapted motor activity and doing them with her husband became a way to share their engagement in the process of care. Furthermore, turning on the tablet together every morning, checking activities, wearing a watch that tracked steps and sleep, and becoming progressively more confident in the interaction with the touch technology enhanced Carla's self-esteem, made her more active in conversations, and fostered her social interconnectedness through domains other than his "memory" difficulties.

From the clinician's perspective, setting Carla's Individual Rehabilitation Plan through the Ability physician's portal and meeting her and her husband for the training session required some extra effort, though still easily manageable, in the organization of the other clinical activities. The opportunity to monitor her vital motor activities from remote, how and when she slept, and how she coped with the dose and type of rehabilitation activities gave the physician a unique opportunity to elaborate on how the rehabilitation program impacted Carla's condition on a week-by-week basis. During the intervention, the clinician could modify the pacing of activities shifting the pause period in different days of the week, and, after noticing that a specific activity was often not accomplished, he could reset the progression rule for increasing difficulty, while asking her husband to support her in not giving up. Moreover, at the end of the program, he could combine the heterogeneous data (performance in cognitive and motor activities, sleep quality, and vital parameters metrics) collected by the Ability platform over the six weeks to give Carla an extensive and articulated feedback about "How it went". This way he could provide a robust basis to consolidate and/or to fix subsequent rehabilitation activities and to foster their therapeutic alliance in the continuum-of-care process.

Target, advantages/disadvantages with respect to current treatment options, technologies needed and main market indicators of the Ability program are briefly shown in Table 1.

Table 1. Target, key features with respect to current treatment options and main market indicators of the Ability program.

Primary users	People with MCI/PWD and formal (neurologist, therapist, neuropsychologist) and informal (e.g. spouse) caregivers
Secondary users	Service center
Target group size	Small
Market size	47.5 million people with dementia in 2015, 76 million estimated 2030
Current treatment/options	Paper and pencil cognitive activities or CD/DVD activities
Cost of current treatment/options	Quite low, considering the cost of consumables to deliver them
Advantages/disadvantages of current treatment/options	They cannot be personalized, they are not adaptable to user's cognitive resources, with risks of loss of motivation, they cannot be monitored remotely and modified until the next specialist visit
Who pays?	The user (in some cases the hospital)
Expected advantages/disadvantages compared to current treatment/options	It is possible to personalize the treatment, monitor it remotely, detect incompliance early, identify the motivation(s) and intervene timely to solve any issue. This will ensure PWD's and caregivers' active participation to the program's activities
From a user perspective, what needs to be resolved before applying the presented solution?	Proof of efficacy
Ethical issues	Privacy issues (data protection, exchange, etc.)

(*continued*)

Table 1. (*continued*)

Technologies needed	Telemonitoring platform and telemonitoring kit (set of devices and gateway)
Fields with shared benefits (synergies)	Serious gaming, wearable technologies, face-to-face multi-component rehabilitation
What is required to make this solution commercially viable?	Regulatory framework and reimbursement model
Incentive for industry, why would industry be interested?	The market is growing rapidly, as dementia is one of the main threats for people's health in the next years. So far there are few/no competitors on the market
Time to market	Short term (less than 3 years)

3 Concluding Remarks

Telerehabilitation has currently gained increasing attention as a rehabilitation strategy for PWD and people in the MCI condition, with evidence of positive effects for cognitive telerehabilitation comparable with face-to-face interventions [14]. At the same time, there are accumulating findings that multicomponent physical-cognitive interventions can improve cognitive status and indicators of brain health in MCI subjects [15, 16].

Based on the Ability platform, the Ability program was therefore designed and developed as an enhancement of usual care programs for people with MCI and PWD through technology. Its main innovation feature is that it promotes a comprehensive home-based continuity-of-care by the combination of: (a) a multicomponent (cognitive and motor activities) telerehabilitation intervention with (b) additional relevant care options like scheduled delivery of the IRP, telemonitoring of vital parameters, and tracking of physical activity. We devised to test its efficacy through a randomized two-treatment arms (Ability Program vs. Treatment As Usual) controlled clinical trial (ClinicalTrials.gov ID: NCT02746484NO; see [17] for full study protocol details), in line with the need to document the efficacy of technology-based interventions through high quality studies. Our expectation is that it will not only serve to mitigate AD progression, but will also benefit the subjective and psychological well-being of MCI subjects and people in early AD conditions, also through the design of the enabling role of technologies in line with the Positive Technology (PT) framework [18]. Such a framework views technologies as interfaces for personal experience, rather than as mere "devices", as in lay perspectives. This way, we envisage to empower social engagement within the care community of PWD and MCI subjects not just as a requirement for compliance with the scheduled activities, but also, being humans an ultrasocial and hyper-cooperative species [19], as the condition enabling the inter-subjective sharing of meaning among all the actors involved in the continuity-of-care process [20].

References

1. Byass, P.: A transition towards a healthier global population? Lancet **386**(10009), 2121–2122 (2015). https://doi.org/10.1016/S0140-6736(15)61476-3
2. Murray, C.J., et al.: Global, regional, and national disability-adjusted life years (DALYs) for 306 diseases and injuries and healthy life expectancy (HALE) for 188 countries, 1990–2013: quantifying the epidemiological transition. Lancet **386**(10009), 2145–2191 (2015). https://doi.org/10.1016/S0140-6736(15)61340-X
3. Winblad, B., et al.: Defeating Alzheimer's disease and other dementias: a priority for European science and society. Lancet Neurol. **15**, 455–532 (2015). https://doi.org/10.1016/S1474-4422(16)00062-4
4. Dubois, B., et al.: Preclinical Alzheimer's disease: definition, natural history, and diagnostic criteria. Alzheimers Dement **12**, 292–323 (2016). https://doi.org/10.1016/j.jalz.2016.02.002
5. Woods, B., Aguirre, E., Spector, A.E., Orrell, M.: Cognitive stimulation to improve cognitive functioning in people with dementia. Cochrane Database Syst. Rev. (2), CD005562 (2012). https://doi.org/10.1002/14651858.CD005562.pub2
6. Jean, L., Bergeron, M.È., Thivierge, S., Simard, M.: Cognitive intervention programs for individuals with mild cognitive impairment: systematic review of the literature. Am. J. Geriatr. Psychiat **18**, 281–296 (2010). https://doi.org/10.1097/JGP.0b013e3181c37ce9
7. García-Casal, J.A., Loizeau, A., Csipke, E., Franco-Martín, M., Perea-Bartolomé, M.V., Orrell, M.: Computer-based cognitive interventions for people living with dementia: a systematic literature review and meta-analysis. Aging Mental Health **21**, 454–467 (2016). https://doi.org/10.1080/13607863.2015.1132677
8. Theodoros, D., Russell, T., Latifi, R.: Telerehabilitation: current perspectives. Stud. Health Technol. Inform. **131**, 191–210 (2008)
9. Kairy, D., Lehoux, P., Vincent, C., Visintin, M.: A systematic review of clinical outcomes, clinical process, healthcare utilization and costs associated with telerehabilitation. Disabil. Rehabil. **31**, 427–447 (2009). https://doi.org/10.1080/09638280802062553
10. Dinesen, B., et al.: Personalized telehealth in the future: a global research agenda. J. Med. Internet Res. **18**, e53 (2016). https://doi.org/10.2196/jmir.5257
11. Martin, M., Clare, L., Altgassen, M., Cameron, H., Zehnder, F.: Cognition-based interventions for healthy older people and people with mild cognitive impairment. Cochrane Database Syst. Rev. (1) (2011). https://doi.org/10.1002/14651858.CD006220.pub2
12. Bahar-Fuchs, A., Clare, L., Woods, B.: Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. Cochrane Database Syst. Rev. (6) (2013). https://doi.org/10.1002/14651858.CD003260.pub2
13. Zygouris, S., Tsolaki, M.: Computerized cognitive testing for older adults: a review. Am. J. Alzheimers Dis. Other Demen. **30**, 13–28 (2015). https://doi.org/10.1177/1533317514522852
14. Cotelli, M., et al.: Cognitive telerehabilitation in mild cognitive impairment, Alzheimer's disease and frontotemporal dementia: a systematic review. J. Telemed. Telecare (2017). https://doi.org/10.1177/1357633X17740390
15. Baglio, F., et al.: Multistimulation group therapy in Alzheimer's disease promotes changes in brain functioning. Neurorehabilitation Neural Repair **29**, 13–24 (2015). https://doi.org/10.1177/1545968314532833
16. Maffei, L., et al.: Randomized trial on the effects of a combined physical/cognitive training in aged MCI subjects: the train the brain study. Sci. Rep. **7** (2017). https://doi.org/10.1038/srep39471

17. Realdon, O., et al.: Technology-enhanced multi-domain at home continuum of care program with respect to usual care for people with cognitive impairment: the Ability-TelerehABILITation study protocol for a randomized controlled trial. BMC Psychiatry **16**, 425 (2016). https://doi.org/10.1186/s12888-016-1132-y
18. Riva, G., Banos, R.M., Botella, C., Wiederhold, B.K., Gaggioli, A.: Positive technology: using interactive technologies to promote positive functioning. Cyberpsychol Behav. Soc. Netw. **15**, 69–77 (2012). https://doi.org/10.1089/cyber.2011.0139
19. Tomasello, M.: The Cultural Origins of Human Cognition. Harvard University Press, Cambridge (2009)
20. Wald, C.: Better together. Nature **531**, S14–S15 (2016). https://doi.org/10.1038/531S14a