2022-07-18

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Recommended Citation

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Abstract. Dementia is a chronic and progressive neurodegenerative illness, which can lead to significant difficulties in a person's capacity to perform activities of daily living and engage in meaningful activities. The Smart Dementia Care project aims to establish an understanding of how best to design digital tools that persons with dementia and their carers will find useful and usable for care planning and goal setting. This paper discusses the first phase of this project and describes how co-design is being used to support engagement in activities of daily living and meaningful activities for people living with the early stages of dementia, with such engagement intended to extend the period of independent living for the person with dementia. It is anticipated that adopting a co-design approach and involving people living with dementia throughout the design cycle will allow for an application that is viewed as usable and intuitive while also acting as a tool of empowerment rather than a burden. At the same time, the intention is that integrating personalized goal-setting functionality focussing on individualized activities and everyday tasks will result in a system that is useful and effective.

Keywords: Dementia, Self-care, Activities of Daily Living, Meaningful Activities, Co-design, Goal-setting.

1   Introduction

Dementia is a chronic and progressive neurodegenerative illness. Dementia affects memory, behaviour, personality and functional and cognitive abilities, results in problems with communicating and reasoning and can lead to significant difficulties in terms of a person's capacity to perform activities of daily living (ADLs) [1, 2]. The estimated number of people globally living with dementia was 50 million in 2018, with this number set to grow to 82 million by 2030 and 152 million by 2050 [3]. Dependency levels can be considered an indication of both disease severity as well as

quality of life (QoL) in PLwD [4]. Cognitive deterioration can impact IADL performance significantly, add to pre-existing functional limitations and contribute to depression due to restricted activity and social participation [5]. With this in mind, it is imperative that strategies are developed to address cognitive decline in order to anticipate and delay the onset of disability and maintain ADL ability among older adults [6]. Specifically, there is a need for an easy-to-use interactive visual care-planning system which reflects the needs and preferences of persons with dementia and allows for active self-management of the condition and shared decision-making with carers.

The Smart Dementia Care project[1] aims to develop a digital toolkit to support someone living with mild-to-moderate dementia, together with their informal carer(s), to self-manage their care, engage in shared decision-making, and to live independently for longer in their own homes. We intend to design a computational goal model of care qualities based on a review of the literature and existing frameworks (see [7]). This will be supplemented with co-design activities to confirm the model and better understand the needs and preferences of PLwDs in relation to their own care goals. The toolkit will allow for the planning and monitoring of personalised care goals, with targets derived from care plans, existing models of daily activities, as well as activities described as meaningful by the individual PLwDs and their carers. It will include a digital visual application for tasks such as setting up personal care plans and goals for daily living activities. The application will be developed using a co-design approach involving PLWDs, their informal carers and healthcare professionals, throughout the design cycle. This paper discusses the importance of participatory co-design when supporting PLWDs' engagement in individualized meaningful activities and ADLs.

2 Background

2.1 Health and Wellbeing

Living well with dementia and providing support around this have become key objectives of public health and research plans internationally [8] with the focus progressing from prolonging life to also enhancing QoL through delaying or preventing further disability [6]. The level of support and help PLwDs require from both family members and carers in general increases over time owing to the progressive nature of the disease, which in turn can result in increased levels of burden and stress among those with the primary responsibility of providing care. For this reason, there is a need for increasing support and assistance to be provided to both the care recipient and the person providing care to ensure adequate care is provided and QoL is maintained [9].

Quality of Life. Lawton's model of QoL (1991) has been highly influential in QoL and dementia research and has driven the approach to and development of QoL in-

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[1] https://www.smartdementiacare.ie

struments [10]. This model suggests assessment should involve both subjective and objective factors and it identifies four main dimensions that contribute to QoL: psychological well-being, behavioural competence, objective environment and perceived QoL [11]. Psychological wellbeing is the subjective evaluation regarding the quality of inner experiences and, according to Lawton, should be viewed as the ultimate outcome of a QoL model [11, 12]. [13] point out that overlap exists with regard to essential features of good QoL as rated by both PLwDs and family carers: positive mood and engagement in pleasant activities.

Activities of Daily Living. Independent living tasks can be categorised into ADLs, which concern basic activities relating to personal care and hygiene, as well as instrumental activities of daily living (IADLs) which are more complex and concern activities needed to function and reside independently in the community [14, 15]. Deficits in basic ADLs are seen to occur primarily once cognitive decline has progressed to the moderate stage, with declines in bathing, dressing, and grooming ability being particularly prevalent beyond this stage [16]. IADLs can be categorised as follows: transportation shopping, managing finances, meal preparation, housekeeping and home maintenance, managing communication, managing medications. In Europe, increased longevity has brought with it an increased prevalence of IADL limitations, which has negative implications in terms of burden placed on healthcare systems [17].

Meaningful Activities. Both PLWDs and their carers have reported that daytime activities, social contact, as well as issues relating to psychological distress comprise the areas of life which are most negatively affected by dementia. The diverse range of interests and abilities among PLwD frequently results in a mismatch regarding services offering daytime and social activities, with PLwDs coming to view such activities as lacking in meaning and value [18]. To design programs which both satisfy psychosocial needs and improve QoL for PLwD, it is therefore crucial to establish what their views and experiences are regarding meaningful activities [19]. The sense of meaning attached to these activities comes from feeling that things matter alongside a sense of pleasure, connection, participation or autonomy. These feelings are apparent and relevant regardless of cognition and dependency levels [20].

2.2   Technology Design for PLwDs

The Co-Design Approach. Co-design as an approach aims to move beyond participation by focussing more on co-production, equal collaboration, and joint decision-making. Co-design techniques in digital health which involve developing a granular understanding of how target end-users spend their day are associated with better adoption of end products across a variety of clinical domains [21]. An important element of co-design in this context is the development of a broad understanding of living with dementia through initial exploratory meetings and discussion with both peo-

ple living with dementia and carers. Holding such meetings in a focus group format with a semi-structured protocol allows for co-questioning and discussion to emerge, revealing insights which may go uncovered within a one-to-one, fixed protocol scenario [22, 9]. Following this, thematic analysis of the meetings can allow for designers to generate ideas around possible technological interventions, solutions or supports which could address issues that arose during the meetings. These ideas can then be brought back to the participants for analysis and feedback during workshops, with ideas viewed as most promising then being refined and further iterated upon [23].

While early stages are likely to feature paper prototypes, issues surrounding cognitive impairment and the need for creative input from the participants may call for functional prototypes to be introduced earlier than design cycles involving participants who are not cognitively impaired. Such an approach was taken by [22] whereby rapid development of functional prototypes was used to mitigate both the potential for memory loss between sessions and the limitations to using paper prototypes with PLwDs. In this case, the prototypes were then personally tailored to individual participants to further limit the need for abstract thinking. Following the development of prototypes, usability tests can be conducted to ensure the design is robust and usable and meets the initial user requirements as laid out in the exploratory meetings, with further iterative design cycles being held should issues continue to arise [24]. In order to address issues that may arise due to cognitive impairment when adopting a participatory approach, [22] suggest a number of strategies: incorporating review into meetings to ensure what was previously recorded is accurate, maintaining a consistent point of contact across meetings so as to reduce confusion, and using existing support groups where possible to allow for familiar environments and participants during meetings while creating opportunities for discussion.

3   Methods

Enabling PLwDs to remain at home for as long as possible while also maintaining a good quality of life is of paramount importance. At the same time, there is an urgent need to deliver more efficient, effective, person-centred care in the community. To achieve this, it is necessary to appreciate and address the needs and preferences of PLwDs in relation to their own care goals. As such, this phase of the Smart Dementia Care project involves requirements gathering and iterative design and testing with relevant end-users of the digital toolkit's visual application and those who care for them.

3.1   Requirements gathering

Semi-structured interviews and focus groups are currently being conducted involving three groups (PLWD, carers, and health professionals working in this area) to allow for in-depth exploration of needs and requirements. Interviews / focus groups will be specific to individual stakeholder groups, i.e. carers will not be present in healthcare professional focus groups and vice versa. However, persons with dementia

can have their informal carers present during any activity if this is more comfortable for them. Topics explored will include what constitutes quality of life for the person with dementia, how to maintain quality of life over time, engagement with ADLs, how engaging in these can contribute to and maintain quality of life and finally what represents meaningful activities. Related to this is the importance of identifying those activities that were valued and enjoyed before the dementia since these are likely to be considered intrinsically meaningful in terms of everyday life and past experience [25]. Interviews will also explore the goals of participants in relation to future health and wellbeing. Participants will be invited to discuss their experiences to date with technology in general, as well as possible technological solutions and supports for activities of daily living and meaningful activities. As recommended by [22], a consistent point of contact will be maintained from the outset so as to create a sense of familiarity and reduce confusion where possible. Following thematic analysis of the interview data, we aim to design and conduct a series of co-design workshops to interactively explore the themes arising from the interviews (and the literature). During the initial co-design sessions, each PLwD will be invited to expand further on activities they find enjoyable, pleasant, or meaningful. They will also be asked to think about activities they would like to continue engaging with in some form going forward. Insights gained from analysis of the initial interviews will also inform a prepared list of activities, which will be used to complement those activities previously elicited by the participants.

3.2   Co-design

Following each workshop, data from the session will be analysed and mock-ups generated based on feedback during the previous session, for presenting and further feedback at the next session. This iterative, user-centred co-design process will ensure the design of a digital application that is useful, meaningful, and usable to participants. Throughout the co-design sessions, methodologies such as personas, scenarios and storyboards will be used to explain technology and design concepts in lay terms to participants, while interactively exploring the themes arising from the interviews and the literature. The aim of incorporating such methodologies is also to clearly contextualise the discussion and illustrate the ways in which the designs could potentially fit into routines and relate to individual activities [9].

The same participants will be involved in the co-design workshops as took part in the interviews phase. Reviews will be incorporated into each meeting to confirm with participants what was previously discussed is accurate and reliable [22]. Each co-design workshop will have a maximum of 5 participants, i.e., 5 persons with dementia (and their carers as needed) or 5 carers. Efforts will be made to ensure both PLwDs and carers feel comfortable to express themselves openly and with adequate time, providing opportunities for separate sessions also should the need arise [22, 9, 24]. Healthcare professionals will also be engaged in some sessions, for example to validate features or content of the application from a clinical perspective. Once initial

prototypes of the application have been developed, usability testing will be carried out with PLwDs and informal carers to ensure robustness and ease of use.

4   Discussion and Conclusion

For PLWDs, self-management involves coping with and adapting to the gradual changes to everyday life that are associated with dementia such to the extent that quality of life is maintained or even improved. Technologies designed for self-management in turn need to consider not only compensation for deficits, but also ways in which positive and meaningful experiences can be highlighted and encouraged [26]. With regard to technology development within dementia care, leisure and activity are now considered among the main areas of interest; this is based on the view that technology may be used beyond the narrow confines of medical care solely, with opportunities also existing to empower and support PLWDs to live a more meaningful life [27, 28]. Designs which focus on and encourage activation of existing capacities can allow for PLWDs to engage in both (I)ADLs and meaningful activities, which in turn should positively affect quality of life [20, 24].

In order for a design to be personally tailored to the individual, it is necessary that the needs and requirements are elicited from the end-user. However, this can become challenging when considering people living with dementia, who at times can struggle to articulate themselves clearly and concisely. As such, multiple stakeholders may be needed to participate in a co-design process to gain comprehensive insight into user needs [28]. For these reasons, the Smart Dementia Care project is adopting a collaborative approach, with end-users co-designing the application from the outset, as well as expert input being provided in the form of interviews and focus groups held with both carers and health professionals.

Following a diagnosis of dementia, it is likely that a person's interests and hobbies will remain as they were prior to diagnosis, highlighting the importance of identifying what these areas are and finding ways to enable the person to continue engaging in activities that align with these interests. It is also important to note that these interests do not necessarily need to be purely related to pleasure or entertainment, and value and meaning for an individual can be found in other areas such as self-management or household tasks and other areas related to IADLs [29]. Seen in this light, encouraging engagement in such activities considered meaningful to the PLWD serves the dual purpose of providing meaning, pleasure and a sense of normality while also supporting the individual's ability to maintain independence in those activities considered necessary for independent living. It has also been suggested that early behavioural interventions aimed at assisting individuals with mild levels of cognitive impairment and their carers to remain engaged in meaningful activities could potentially decelerate the rate of cognitive decline while also addressing changes in relationships and mood [30]. This phase of the Smart Dementia Care project aims to conduct user-centred research and design activities to support the development of a digital application for planning and monitoring personalised care goals for people with dementia,

focussing on both activities of daily living and activities considered meaningful to the individual. It is anticipated that the proposed system, once designed to fully meet the user requirements determined during the co-design phase, will allow for quality of life to be maintained or improved, while also supporting the PLWD to live independently for longer in their home.

Acknowledgements

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