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Co-designing Assistive Technology with and for Persons Living with Dementia

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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 (ADLs) and engage in meaningful activities. There is an acute need, which digital health technologies can potentially fulfil, to provide proactive support for persons living with dementia (PLwD) and their caregivers. However, there is limited involvement of PLwD in the design of technology that could be used to support their personal plans for independent living at home. In this paper, we describe how we are employing a co-design methodology to support engagement in an assistive technology toolkit for managing ADLs for people living with the early stages of dementia.

Keywords-co-design; assistive technology; dementia.

I. INTRODUCTION

It is estimated that close to 50 million people globally are living with dementia and that each year there are 9.9 million new cases of dementia worldwide [1]. According to research carried out by the Alzheimer Society of Ireland (ASI), an estimated 64,000 people are living with dementia in Ireland [2]. Increasing age remains the strongest risk factor for dementia, with prevalence rates nearly doubling every five years over the age of 65. With an aging population, the number of people with the condition will more than double in the next 25 years to over 150,000 by 2045, representing 2.5% of the Irish population [2]. PLwD have higher utilization of healthcare services and higher healthcare costs than those without dementia [3]. From a carer perspective, half a million people in Ireland have a family member with dementia. The care burden associated with dementia is significant and a recent meta-analysis found dementia family caregivers to be significantly more stressed than non-dementia caregivers and to suffer more serious depressive symptoms and physical problems [4]. The Irish Health Service Executive and ASI advocate that people with dementia who want to remain in their own homes should be supported to do so for as long as possible with high quality home care services.

There is an acute need, which digital health solutions can potentially fulfil, to provide proactive support for PLwD and their caregivers. However, there is limited involvement of people with dementia in the design of technology that could be used to support their personal plans for independent living. The majority of dementia technology is focused on

monitoring, security and safety [5]-[7]. The primary user of these types of technologies is typically the carer, while the PLwD is often a passive user.

Our research aims to bring together a multidisciplinary team to co-design new assistive technologies with and for PLwD. Specifically, we are focused on developing a digital toolkit to support someone living with mild-to-moderate dementia, together with their informal carer(s) to plan and monitor personalized 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. The toolkit will include a visual application for tasks, such as setting up care plans and goals for ADLs. This paper discusses the importance of co-design methods to support PLwDs' engagement in the design of technology to support their care.

II. BACKGROUND

A. Quality of Life (QoL)

Lawton's model of QoL [8] has been highly influential in QoL and dementia research and has driven the approach to and development of QoL instruments. This model suggests assessment should involve both subjective and objective factors and it identifies four main dimensions that contribute to QoL: psychological well-being, behavioral competence, objective environment and perceived QoL.

B. Activities of Daily Living (ADLs)

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 [9]. IADLs can be categorised as follows: transportation shopping, finances, meal preparation, housekeeping, managing communication and medications.

C. 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. 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. The

sense of meaning attached to these activities comes from a sense of pleasure, connection, participation or autonomy. These feelings are apparent and relevant regardless of cognition and dependency levels [10].

III. METHODS

A. Recruiting Participants

We aimed to recruit individuals with a diagnosis of Mild Cognitive Impairment (MCI) or early-stage dementia. Participants were recruited through two sources: the ASI or through a local outpatient referral centre for older adults. Recruited Occupational Therapists (OTs) all worked at the same outpatient referral centre, which specializes in assessing and managing cognitive impairments, most common types of dementia, frailty syndromes, as well as a variety of other diseases associated with ageing. Information leaflets describing the study were provided and clinicians made the first approach to potential participants. The aims, procedures, risks, and benefits were outlined, and the clinicians provided an overview of the study. Participants needed to be able to understand the study requirements and give informed consent. We recruited five PLwD and five of their informal carers, as well as five healthcare professionals. Prior to the study, ethical approval was received from the university and health service research ethics committees.

B. Data Collection

Participants initially took part in interviews or focus groups to explore requirements in detail. Following a review of the literature, data was collected from participants about the following topics - what constitutes QoL for them, how to maintain QoL, the relationship between engaging in daily activities and maintaining QoL, and which activities bring meaning and why. Participants' discussed how technology could support them in engaging in and maintaining ADLs for better QoL. Interviews and focus groups with healthcare professionals provided a clinical perspective of what is important for self-care and care planning for PLwDs and their carers and how technology can support self-care and care planning for dementia. PLwD and informal carer participants also took part in a series of four co-design workshops to co-design the toolkit. Interviews and focus groups were conducted face-to-face in individual participant's homes as well as online due to Covid-19 restrictions. Participants had the option to participate in the interview with their informal carers and four out of five participants opted to do this. Sessions were audio recorded using Zoom or using a dictaphone for face-to-face sessions. Co-design workshops took place in a research centre and involved all of the PLwD and informal carer participants together.

C. Data Analysis

Analysis is currently ongoing. Transcripts are being thematically analyzed in NVivo (qualitative data analysis software) following the six-step approach outlined in Braun and Clarke [11], to provide a framework for identifying the themes or patterns within the data.

IV. DISCUSSION

Technologies for self-management for PLwD need to consider not only compensation for deficits, but also ways in which positive and meaningful experiences can be highlighted and encouraged. We are developing an assistive technology toolkit for PLwD for maintaining ADLs and meaningful activities. The toolkit will be evaluated in a field trial later this year and a series of questionnaires, including CASP19 for QoL [12], will be used to evaluate effectiveness of the toolkit for managing ADLs for PLwD.

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