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Abstract— **For people with early or moderate dementia, there are benefits to them continuing to live in their own homes for as long as possible, both in improved quality of life and associated measures such as increased social contact, increased physical activity and lower use of medication, and reduced costs and burden of care. Tools to help extend period of independent living, and to maintain quality of life in this period, are lacking. Systems exist to monitor individuals for problems, e.g. falls or wandering from the home, but there is scope for development of computerised support to help maintain activity in independent living. We aim to monitor achievement of activities, by app and by sensors, and provide recommendations on how to best maintain activities.**

Keywords- dementia; goal modelling; self-care; independent living.

I. INTRODUCTION

Dementia is a set of symptoms that may include deterioration in memory and ability to focus attention, unpredictable behaviour and decline in the ability to perform routine activities of everyday living. It can be caused by a number of conditions, with Alzheimer's disease being the most common cause of dementia [1]. Dementia symptoms are progressive and the disorder is incurable; Persons Living With Dementia (PLWD) require increasing care as their underlying disease progresses. Currently, it is estimated that about 50 million people worldwide suffer from a form of dementia, with this number projected to rise to more than 131 million by 2050, reflecting aging populations around the world [2]. As well as the human cost of the disease, there is a societal financial burden, estimated to be over $1 trillion a year worldwide, with 80-85% due to paid social care services and unpaid informal family care [3]. For people with early or moderate dementia, there are benefits to them continuing to live in their own homes for as long as possible, both in improved quality of life and associated measures such as increased social contact, increased physical activity and lower use of medication, and reduced costs of care [4]. Lower physical function is associated with increased risk of admission to long-term care, and so it is beneficial to maintain physical function for as long as possible [4]. It

should be noted that only a minority of PWLDs will move into a care home [5].

The Smart Dementia Care project aims to develop a computerised toolkit to assist people with early-stage dementia to live independently in their own homes. This toolkit will support a PLWD and their family carer(s) in developing a personalised care plan, encourage each PLWD's compliance with their care plan, and will incorporate goal targets derived from care plans, existing models of daily activities, and activities defined by the individual PLWDs and their carers. The project is following a co-design methodology where the research team includes PLWDs as experts in their condition. Achievement of goals by a PLWD will be measured by a combination of self- (or carer-) reporting via an app, and automatic data collection from body-worn or static sensors. The app and sensor data capture are under development in parallel. In this paper, we focus on the development of a computational goal framework to enable the specification of goals by PLWD and the capture and quantification of goal achievement data.

Persons with dementia should be at the centre of decision-making about their care including basic activities (e.g., feeding, dressing), advanced activities (e.g., finances, using transportation), and meaningful activities (e.g., social and recreational pastimes). However, there is limited involvement of people living with dementia in the design of technology to support their care. We describe the early development of a goal framework to enable personalisation of goals and tracking of goal achievement for persons with an early-stage dementing illness with the aim of promoting independent living at home. Goals are developed from existing measures of human ability and disability, from activities defined in care plans, and activities that individuals desire to maintain as pleasurable activities. We present an initial outline of our framework, that includes the capture of information pertaining to each goal in each individual's personalised goal schedule, comparison of achievement with their personal target for included activities, and suggested actions to take in the case of under-achievement. The rest of this paper is organized as follows. Section II describes the process of selection of activities to be monitored. Section III

describes the chosen activities. Section IV discusses possible burdens on PLWDs of this work. Section V gives conclusions and an akcnowlegement.

II. METHOD

We wish to encourage PLWD to achieve goals that will help maintain their ability to live independently in their own homes for as long as possible and which will help them retain those activities that will continue to benefit quality of life for those who may move from their own home into residential care.

In particular, we wish to encourage PWLDs to perform activities that fall into one of three groups:

(i) Basic Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). These activities are the most basic activities that allow individuals some degree of independence, which for ADLs include ability to bathe oneself, select clothes and dress oneself in the correct sequence, toileting, transfer, continence and feeding [6] and for IADL are the more sophisticated instrumental activities such as shopping, meal preparation, laundry and money management [7].

(ii) Activities defined in their care plans. Care plans are agreed between health and care professionals, PLWD and their family carers. They are documents that record the care needs of a PLWD and their carers. Care plans may include information about accessing services, monitoring co-morbidities, a named healthcare contact, and details of activities that the PLWD should aim to continue. The plan may include goals which may be related to performing specific activities. These care plans are relatively static, often paper-based and reviewed annually, not computerised or interactive, and so the degree of responsive personalisation for each PLWD is limited.

(iii) Activities that bring pleasure or satisfaction to PLWD. Example sets of such pleasurable activities exist but it is unlikely that any one PLWD will wish to enjoy all activities in any one defined set, and they may have wishes to enjoy activities that are not in any existing sets of pleasurable activities. In proposing and selecting pleasurable activities, we take inspiration from work from such organisations as the NHS [8]

In order to achieve our aims of extending the period spent in independent living and maintaining the quality of life in independent living, ADLs and IADLs will be standard for all PLWD, but other activities will be personalised using the care plans and wishes of each individual PLWD. Monitoring changes in goal achievement over time allows for a greater degree of personalisation for each PLWD. We reviewed the literature relating to basic activities of daily living, including scales used in determining the abilities and disabilities of PLWD and any goals for these basic activities. Similarly for pleasurable activities we reviewed the literature relating to measuring the frequency and degree of such activities and of related emotions.

III. RESULTS

Goal-oriented Cognitive Rehabilitation (CR) is a form of therapy which aims to address and manage functional disability and maximise social participation and engagement using a person-centred, goal-oriented and problem-solving approach [9]. It uses evidence-based rehabilitative methods and involves PLWDs and their carers or family members working together with a therapist to identify meaningful and personally relevant goals related to everyday activities [10]. Strategies are collaboratively devised and implemented; evaluation in terms of progress towards goal attainment is based on both participant and informant-reported information [9][11]. A multicentre randomized controlled trial by Clare et al [9] demonstrated that PLWDs were able to identify goals they felt were important and were motivated to address and attempt to attain. In addition, results from their trial suggest that an individualised and goal-oriented implementation of CR can lead to improvements in everyday functioning, and it can be an effective intervention for people with early-stage dementia. One of the fundamental strengths identified from Clare et al's work was the possibility of transfer and generalisation, with the goals that were identified and worked towards being relevant and applicable to improved functioning in real-world situations. Moreover, the suggestion has been made that once delivered in a cost-effective manner, CR could be integrated into care pathways with a view to developing strategies for living with dementia in the community [9].

Phinney et al [12] identified four categories of goal, based on interviews with and observations of PLWDs: (1) leisure and recreation; (2) household chores; (3) social involvements; (4) work-related. Interview participants stressed the importance of being able to continue engaging in these activities and the willingness to employ new strategies to do so should this be required as the disease progresses. Related to this is the importance of identifying those activities that were valued and enjoyed before the onset of dementia since these are likely to be considered intrinsically meaningful in terms of everyday life and past experience [12].

The Goal Attainment Scale (GAS) [13] has been used to measure achievement of goals in dementia, but GAS itself is not specific for dementia and the particular goals used in any analysis are selected in cooperation with the PWLD. There are a number of scales used to measure individuals' performance and disability, e.g., [14], but we found only two scales that were specific for PLWDs: The Pleasant Events Schedule for Alzheimer's Disease (PES-AD) of Teri & Logsdon [15] and the Dementia Quality of Life (DEMQOL) questionnaire of Smith et al [16].

(i) Basic activities of daily living. The long-established ADL scale of Katz [6] and IADL scale of Lawton and Brody [7] measure the ability of individuals to perform basic activities of daily living. These scales were created to allow scoring of the degree of self-maintenance functions that individuals are able to perform for themselves, with the Katz scale measuring more basic functions than the Lawton-Brody scale. It is important for these activities to be maintained for as long as possible both for those with dementia and those without dementia, but for those with some forms of dementia (including Alzheimer's), once the ability to perform an activity is lost, it cannot be regained. In Ireland, the Modified

Winchester Disability Scale (MWDS) [17] dominates assessment of risk in the elderly. Additional to the ADL and IADL scales it includes mental and social activity. It should be noted that none of these scales are specific for PWLD. Example activities measured by these three scales include the ability to bathe oneself; ability to select clothes and dress oneself appropriately; the ability to make telephone calls; ability to shop for oneself; and mobility.

(ii) Activities in individuals' care plans. Formal Care Plans contain a variety of information useful to the PLWD and their family carers, and are usually drawn up in cooperation with health professionals. They can include such useful and essential information as medication and prescriptions details, emergency telephone numbers, allergies, etc. They can also include a set of activities that are essential and/or enjoyable to the PLWD, such as personal hygiene; going for a walk; preparing lunch; gardening. Examples of the possible content of a care plan can be found in [18]. Should such activities be present in a care plan they can be included in the toolkit.

(iii) Enjoyable activities. The set of activities in this group will be tailored to each PLWD and are chosen because they bring pleasure to that person and/or have other benefits, such as the health benefits gained from an enjoyable walk, that can help maintain quality of life. Each PLWD, or their carer, will be asked to describe activities such as socialising, hobbies or exercising that the PLWD enjoys and wishes to maintain. From this list of activities, a set of activity goals will be agreed on and included in the individual's set of goals to be achieved. Additionally, a prepared set of activities, derived from our literature review and from co-design sessions attended by PLWD and their carers, will be presented to PLWD and their carers as prompts to ensure that they have not omitted any activities that they do enjoy but may not recall unprompted in interview. Two scales that measure pleasurable events or emotions in dementia were found: Teri and Logsdon's PES-AD [15], a set of activities and events created to measure the quality of life of individuals with Alzheimer's Disease, and Smith et al's DEMQOL [16]. Smith et al focused on recording changes in emotional states, whereas Teri & Logsdon focused on the accomplishment of actual events. Our list is based on the PES-AD scale. Example PES-AD activities include: Having friends visit; doing jigsaw puzzles; gardening; going to church.

ADL, IADL and PES-AD activity sets were each drawn up several decades ago and some activities included, for example making a telephone call, need to be updated to allow for communication using mobile phones, email, or social media. Other activities may need to take into account restrictions due to the current COVID-19 pandemic, e.g., 'going to church' may need to also allow for 'attending church services remotely'. Additional activities will be identified through co-design workshops attended by PLWDs and their family carers.

We aim to determine goals for each of the established ADLs and IADLs, and to measure each PLWD's achievement in reaching these goals. Further, for each PLWD, we take individualised goals from their care plans

and from activities pleasurable to them, again measuring their achievement of these goals. Measurement of these goals will be either by PLWD or their family carer entering information directly into the toolkit interface, or by automated data collection by sensors.

For each activity included, for example 'ability to shop for oneself' or 'going to church', a decision needs to be made on the appropriate metric to determine achievement of each goal, and how to measure achievement of the goal. We aim to establish baseline target goal levels based on the PLWD's existing performance in order to maintain performance of activities and improve wellbeing.

Existing scales of daily activities and pleasurable activities can be utilised to create a set of goals for individuals with dementia. Achievement of these goals by PLWDs can benefit their quality of life and help them maintain their ability to live independently. Achievement of these goals can be directly reported by PLWDs or their family carers via a computerised toolkit's interface, or can be determined by data collected by sensors. Information recorded for each activity will include quantifiable information such as start time, end time, duration, achievement, comparison with goal target, and a measure of pleasure or satisfaction. For example, a PLWD may have had a daily walk starting at 10am and finishing at 10:45am, lasting 45 minutes, walking for 2.5 km and exceeding a target of 2 km. The measurable achievement score – in this case 45 minutes, 2 km – can be tracked over time, providing information to the PLWD and their carers about which areas of their daily life may require attention, potentially in the form of advice in improving achievement.

Examples of some goals are shown in Table 1. Included in the table is information on each goal, illustrating how we intend to quantify the achievement of each goal.

Each example in Table 1 shows a different type of goal. 'Preparing a meal', an IADL, is a basic activity we wish to encourage the PLWD to maintain as essential for continued independent living. 'Walking' is often included in care plans

TABLE 1. GOAL TARGETS AND THEIR MEASUREMENT

Activity source:	(I)ADL/ MWDS	Care plan	PLWD/ Carer
Specific activity:	Preparing a meal	Walking outside	Visiting a friend
Optionality:	Core	Core	Optional
Frequency goal:	Once a day	Once a day	Once a week
Duration goal:	20 minutes	60 minutes	120 minutes
Duration data source:	Sensors/ app	Sensor	App
Achievement goal:	Successful preparation	Walk 2.5 km	Visit friend
Average frequency:	5/week	6/week	0.8/week
Average duration:	24 minutes	55 minutes	140 minutes

for the health benefits it brings. 'Visiting a friend' is a little different from the previous two activities, as it is included as being chosen by the PLWD as a pleasurable activity that helps maintain their quality of life. Each activity has several dimensions that can be quantified: duration of activity, frequency of activity, activity achievement (e.g., distance walked, completeness of meal preparation). Measurement of these dimensions can be recorded by sensors, by asking the PLWD or their family carer to enter information on goal achievement into an app, or by a combination of the two. Using this approach allows for finer granularity of information to be captured than the traditional paper-based recording of ADL performance, and allows for the information to be captured in real-time or near-real-time rather than the usually retrospective information capture necessitated when information is gathered by visiting healthcare professionals.

IV.   DISCUSSION

In order to record achievement of activities, whether (I)ADLs or pleasurable activities, data on achievement of activities must be captured. This can be done by sensors, with little or no demand on the PLWD, or by active data entry by the PLWD. We believe that of the 13 ADL and IADL activities, 8 can be monitored by use of sensors (e.g. 'bathing'), leaving 5 that will require manual entry by the PLWD (e.g. 'shopping'). The intention of the co-design methodology is that, by engaging with PLWDs at the app design stage, the app will be simple to use and be seen by the PLWD as a device of empowerment rather than a burden. By including activity reminders and goal targets it is intended that the app be a useful tool, and our early feedback from carers is that this will be the case. However, we await the outcome of the full co-design sessions and feedback on use of the developed app to confirm or otherwise that this is the case.

There is some literature on behaviour change, such as the work of Fogg et al [19], Oinas-Kukkonon [20], Reimer et al [21] and Webb et al [22], which will inform our work on assisting PLWD to continue to maintain good behaviours. in particular, Fogg et al's categorisation of new behaviours into 'one-time', 'temporary' or 'permanent'. We take further inspiration from the transtheoretical model of health behavior change of Prochaska and Velicer [25], in particular because we are aiming at maintaining activities of PLWDs rather than changing them.

Success of our system will be measured by recording period of independent living against existing times, rate of decline in performing activities, and adherence to self-reporting of activity performance. Limitations on our work are the engagement of PLWDs and their carers, the technology challenges of tracking activities by sensors, and the appropriate selection of activities and activity achievements.

V.   CONCLUSIONS

A set of goals for PLWDs can be constructed from existing scales of performance and disability, including scales that are not specific for dementia and those that are, and from care plans. Additional goals can be included following discussion at co-design workshops and interviews with individual PLWD. Goal targets can be determined from care plans, from existing achievement levels of PLWD and achievement ambitions. The set of goals and goal targets can be used to construct a framework that will allow for computational models to determine goal achievement and suggestions to maintain or achieve goal targets.

Future work will include developing methods of capturing goal achievement information with minimum burden to the PLWD, by using an app with a simple interface and/or capturing and processing data automatically from sensors; developing appropriate methods of prompting or encouraging PLWDs to achieve or repeat goals, and mapping relationships and dependencies between goals (for example, the ability to walk or drive a minimum distance, or the ability to use public transport, which may be necessary for the ability to perform independent shopping). A pilot implementation of the system in the homes of 6 PLWDs is planned, to include evaluation of activity achievement, and burden on the PLWDs and their carers.

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