

Individualized Self-Care for Early-Stage Dementia: A Framework for Activity Attainment and Replacement

Jonathan Turner, Ciarán Nugent, Damon Berry,
Dympna O’Sullivan
Department of Computer Science
Technological University Dublin
Dublin, Ireland
email: jonathan.turner@tudublin.ie,
ciaran.nugent@tudublin.ie, damon.berry@tudublin.ie,
dympna.osullivan@tudublin.ie

Michael Wilson, Ann Marron, Julie Doyle
NetwellCASALA
Dundalk Institute of Technology
Dundalk, Ireland
email: michael.wilson@dkit.ie, ann.marron@hse.ie,
julie.doyle@dkit.ie,

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, lower use of medication, and reduced costs and burden of care. Tools to help extend the 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. We describe a goal model to monitor achievement and to suggest replacement activities and goals when an activity goal can no longer be achieved.

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

I. INTRODUCTION

We report on our work on assisting Persons Living With Dementia (PLWDs) in living independently for as long as possible and with as much Quality of Life (QoL) as possible, work previously discussed in [1]. Dementia is a set of symptoms that may include deterioration in memory and the 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 in older people, contributing to 60-70% of cases [2]; other common causes of dementia are vascular dementia, Lewy Body dementia and fronto-temporal dementia [3]. Dementia symptoms are progressive and the disorder is incurable; Persons Living With Dementia (PLWDs) require increasing care as their underlying disease progresses. Different types of dementia progress in different ways and at different rates but overall the disease is one of irreversible decline. There is evidence to suggest activity-based therapies can slow this decline, for example physical exercise [4]. 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 [5]. As well as the human cost of the disease, such as demands on family members acting as informal carers [6], there is a societal financial burden, estimated to be over \$1 trillion a year worldwide, with 80-85% of these costs due to paid social care services and unpaid informal family care [7]. For people with early or moderate dementia, there are benefits to them exercising their personal preference of continuing to live in their own homes for as long as possible, both in improved QoL and associated measures such as increased social contact, increased physical activity and lower use of medication, and reduced costs of care [8]. 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 [8]. It should be noted that only a minority of PLWDs living in their own home will move into a care home [9].

The Smart Dementia Care project [10] 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 informal family carer(s) in developing a personalised activity plan and will encourage each PLWD’s compliance with their activity plan. The activity plan will incorporate goal targets derived from formal care plans, existing models of daily activities, and activities defined by the individual PLWDs and their carers as being activities that the PLWD finds rewarding and wishes to continue. The project is following a co-design methodology, where the research team includes PLWDs as experts in their condition and their lived experience of it. Achievement of goals by a PLWD will be measured by a combination of self- (or informal carer-) reporting via an app, and automatic data collection from body-worn or static sensors utilizing a variety of technologies, for example proximity sensors, humidity sensors, location sensors or motion sensors. The app and sensor data capture are under development in parallel with the work described in this paper. In this paper, we focus on the development of a computational goal framework to enable the specification of goals by PLWDs and the capture and quantification of their goal achievement data.

Persons with dementia should be at the centre of decision-making about their care and the regular activities that form part of their care [11] including basic activities (e.g., feeding themselves, dressing themselves), advanced activities (e.g., managing finances, using transportation), and activities meaningful to the individual PLWD (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 and their ability to live independently by helping them maintain the performance of activities required for the continuation of independent living.

According to a report investigating older people's preferences for care in Ireland, the majority of people with dementia would prefer to remain at home and in their community for as long as possible, utilising home-care support as an alternative to long-term residential care where possible and where feasible [12]. This is reflected in a report for the UK Alzheimer's Society [13] which states that 85% of people in the UK would prefer to remain living in their own homes following a dementia diagnosis [14; 13]. A central goal therefore is to enable people to remain in their homes for as long as possible while also providing care that is safe, timely, efficient, and as close to home as possible. As well as this, emphasis is placed on maximising the integration of natural supports such as family, friends, and social interaction.

The scope for assistive technology to play a role has been recognised as having the potential to improve QoL for both the person living with dementia and their informal carer(s), reduce carer stress, and foster and maintain a sense of independence and autonomy for the PLWD and those involved in providing care and support [15]. However, while there has been an increase in the development of technologies to support PLWDs, there remain gaps in healthcare technologies for self-management which provide support to PLWDs and their informal carers in their homes.

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 formal personal care plans, and activities that individuals desire to maintain as pleasurable or otherwise meaningful and so which enhance QoL. 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, whether that be persistent or short-term 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 and the selection of replacement activities. Section IV discusses possible burdens on PLWDs of this work. Section V gives conclusions, description of further developments of this work and an acknowledgement.

II. METHOD

A. Activities and goals

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 [16]. 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 [17]. Strategies are collaboratively devised and implemented; evaluation in terms of progress towards goal attainment is based on both participant and informant-reported information [16; 18]. A multi-centre randomized controlled trial by Clare et al. [16] demonstrated that PLWDs were able to identify goals they felt were important and were motivated to address and attempt to attain and retain. 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 being worked towards being relevant and applicable to improved functioning in real-world situations. Moreover, the suggestion was made by Clare et al. 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 [16]. The Goal Attainment Scale (GAS) [33] has been used to measure achievement of goals in dementia. GAS itself is not specific for dementia and the particular goals used in any analysis for PLWDs are selected in cooperation with the PLWD. Table 1 shows an implementation of a GAS for the work described here, adapted from Turner-Stokes [20].

Phinney et al. [21] 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 goals. 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 [21].

We wish to encourage PLWDs to achieve goals in activities that will help maintain their ability to live independently in their own homes for as long as possible and which will give them the greatest QoL as possible.

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

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/ Self-report	Sensor	Self-report
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

(i) Basic Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). These activities are the most basic activities that together allow individuals some degree of independence. ADLs are the ability to bathe oneself, select clothes and dress oneself in the correct sequence, toileting, transfer, continence, and feeding, activities defined by Katz et al. in 1963 [22] and now well-established. IADLs are the more sophisticated instrumental activities of making a telephone call, shopping, meal preparation, using transportation, doing laundry, and financial management, activities defined by Lawton and Brody in 1969 [23] as being those that enable independent living and are similarly now well-established. Each of these scales measure the ability of individuals to perform basic activities of daily living and activities required for independent 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, the most common form), once the ability to perform an activity is lost, it cannot be regained. Retaining the ability to perform ADLs will benefit PLWDs even after they can no longer live independently. In Ireland, where this work is being performed, the Modified Winchester Disability Scale (MWDS) [24] dominates assessment of risk in older adults. Additional to the ADL and IADL scales it includes measures of mental and social activity. It should be noted that none of these scales are specific for PLWDs.

(ii) Activities defined in individuals' formal care plans. Care plans are agreed between health and care professionals, the PLWD and their family carers. They are documents that record the care needs of a PLWD and their informal carers. 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 (see, for example, the discussion on care plans in Burt et al. [25]). 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. The plan can include goals which may be related to performing specific activities. Examples of the possible content of a care plan can be found in [26]. These care plans are relatively static, often paper-based and reviewed only annually, not computerised or interactive, and so the degree of responsive personalisation for each PLWD is limited. Should such activities be present in a care plan they can be included in the toolkit.

(iii) Meaningful activities (MAs): Meaningful activity can be described as any activity that results in emotional, creative and intellectual stimulation, while also providing increased levels of wellbeing and QoL over the course of an adult's life [27]. Engagement in meaningful activity has been found to positively affect overall health and wellbeing in a number of ways, including increased positive emotions, improvements in ADL performance, improved overall QoL and well-being, positive relationships with carers, and reduced behavioural symptoms [28]. Activities comprise a broad range of tasks and endeavours, ranging from household chore to recreation and social involvement. In essence, they are activities that bring pleasure or satisfaction (i.e. they have meaning) to PLWDs.

Example sets of such MAs exist, e.g. Mahoney and Barthel [29], 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 the use of MAs as a therapeutic tool, we take inspiration from work from such organisations as the NHS [30]. 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, for example, an enjoyable walk, that can help maintain QoL.

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 with the PLWD and included in that 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 PLWDs 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 [31], a set of activities and events created to measure the QoL of individuals with Alzheimer's Disease, and Smith et al.'s DEMQOL [32]. These scales focus on QoL rather than basic activity achievement. Smith et al. focused on recording changes in emotional states, whereas Teri & Logsdon focused on the accomplishment of

actual events. Our initial list is based on the PES-AD scale. Example PES-AD activities include: Having friends visit; doing jigsaw puzzles; gardening; going to church. Each MA has associated with it a number of attributes that are required to perform that activity, which may be ADLs, IADLs, exercise specific functions, or bring other benefits.

B. Activity selection

In order to realise our aims of extending the period spent in independent living for PLWDs as much as possible, the expectation to exercise ADLs and IADLs will be standard for all PLWDs, with the caveat that new activities should not be introduced for PLWDs who had not previously routinely performed that activity (shopping, or preparing meals, for example). Performance of ADLs and IADLs will be regularly monitored. Other activities – the MAs - will be personalised using the formal 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.

MAs have associated with them a number of attributes. As well as the ADLs and IADLs that may be exercised during the achievement of a MA, there are also benefits from exercising cognitive functions, and the benefits of improved QoL. The American Psychiatric Association [33] defines the cognitive functions as Learning and memory; Language; Executive function; Complex attention; Perceptual-motor; Social cognition. Tuijt et al. [34] identified six domains of meaningful or enjoyable activities into which activities could be categorized: physical activity; looking after my household; enjoyable and leisure activities; hobbies and personal interests; staying mentally active; and social activities/community involvement. Should a PLWD no longer be able to perform a MA, they may lose the QoL benefit of performing the activity and may also lose the more basic benefits of performing the ADLs and the IADLs, and of exercising the cognitive functions that may have been exercised by that activity. In order to maintain the benefits of the lost activity, it is proposed to suggest to PLWDs possible replacement MAs. Replacement MAs will be selected and ordered using, in the first iteration, a simple machine learning method, 'k nearest neighbours' [35]. This method uses attributes of an entity to identify closely matching entities from a set (in this case, using the IADLs, cognitive functions and domains fulfilled by exercising the 'lost' MA to identify MAs in the master set that most closely match the attributes of the 'lost' MA).

ADL, IADL and PES-AD activity sets were each drawn up several decades ago and some activities included could benefit from updating. For example 'making a telephone call' should now allow for communication using SMS, email, or social media, as well as voice calls, using landline telephones, mobile telephones, tablets or laptop computers.

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. To achieve this, Lindsay et al. [36] suggest including carers in meetings to provide support during discussions where communication issue arise while also paying close attention to instances where the carer may speak on the care recipient's behalf. It has also been pointed out that operating separate interviews and workshops for people living with dementia and for carers can allow participants to express themselves freely without either being spoken over (in the case of the person living with dementia) or feeling reluctant to discuss negative aspects of the caring process (in the case of carers) [37, 38]. At the same time, it is important to consider that carers and family members may eventually become the primary user and facilitator of these technologies due to declining abilities and the progression of the disease.

Goals will be determined for each PLWD 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 formal care plans and from their chosen MAs, 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 where this is feasible.

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. Performance of these goals by PLWDs can benefit their QoL 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. This activity exercises some cognitive functions (Executive function; Complex attention; Perceptual-motor) and has QoL benefits from the 'enjoyable and leisure activities' domain. 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.

III. RESULTS

Examples of some typical goals are shown in Table 2. Included in the table is information on each goal, illustrating how we intend to quantify the achievement of each goal. ADLs are not included in the set of explicitly monitored activities since they are measured on a binary achievement scale which will be achieved by all PLWDs in the early stages of dementia, and which do not in themselves allow PLWDs to maintain independent living. Where possible, it is intended to monitor the performance of ADLs by use of sensors to capture information regarding achievement of ADLs, for example the time taken to get dressed, to monitor any gradual decline in performance of achieved ADLs.

Each example in Table 2 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 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 QoL. 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 contemporaneously rather than the usually retrospective information capture necessitated when information is gathered by visiting healthcare professionals.

Activity information is collected daily from the app and from sensors, and added to the historical data. Information relating to that day's activities is then analysed. In particular, that day's activities performance is compared to the targets for each activity. For those activities where the target is met,

the target is met, an appropriate encouraging confirmatory message is sent to the PLWD. Background analysis of the performance of the activity over time is also performed to see if there is a measurable decline or improvement in activity performance, irrespective of whether the target has been achieved. For activities which are not achieved, the initial action is to send a message to the PLWD to either remind them to perform the activity or to encourage them to improve their performance. If it becomes apparent that a MA is no longer being achieved with any regularity, then a replacement MA (or set of replacement MAs) is chosen for recommendation to the PLWD. Determination of replacement MAs is based on the continuation of achievement of the attributes intrinsic to the achievement of the 'lost' MA. These attributes may be IADLs, skills and/or themes.

Table 3 shows an example of a MA that might be chosen by a PLWD as an activity that had meaning to them and that they enjoyed on a regular basis, and includes a small subset of other MAs for comparison. For the purposes of the examples, it has been assumed that the preferred MA, 'coffee with friends', involves travelling to a coffee shop, purchasing items in the shop, and socializing with friends. Thus the 'travelling' IADL is being exercised, the 'perceptual-motor', 'complex attention', 'language' and 'social cognition' skills are being exercised, and meaning is achieved in the 'enjoyable/leisure' and 'social/community' domains. When this MA, 'coffee with friends', is no longer being achieved on a regular basis, the achievement of the particular IADLs, the exercising of particular cognitive functions and the pleasure gained from particular domains may be lost. The table includes indication of which IADLs, cognitive functions and domains are fulfilled when the MA is achieved. If this MA is no longer being achieved then alternative activities that exercise the IADLs, cognitive functions and domains should be adopted. Suggestions are made to the PLWD (or their informal carer) of possible alternative activities (or sets of activities) that can exercise the IADLs, cognitive functions and domains that are not exercised if an MA is no longer achieved. Potential replacement activities are selected from the existing set of MAs according to how well the potential replacement MA matches.

To select candidate MAs for suggestion to a PLWD as potential replacements for a lost MA, the full set of MAs is examined to find those MAs that most closely match the MA that is no longer being performed. Note that Table 3 shows only a small subset of the set of MAs maintained for this study, for illustrative purposes. The full set of MAs is based on the work of Teri and Logsdon [31] with additions from PLWDS in this study who suggest MAs that are meaningful to them. The closeness of matching of candidate replacement MAs to the lost MA is calculated using a simple k nearest neighbours method, chosen for its simplicity and explainability. For the knn distance between activities, the simplest calculation method is employed, that of the number

TABLE 2. 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/ Self-report	Sensor	Self-report
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

TABLE 3. SOME MEANINGFUL ACTIVITIES AND THE ATTRIBUTES THEY EXERCISE

	MA:	Coffee with friends	Being outside	Video meeting with friends	Gardening outdoors	Having friends visit for lunch
Activity type	Attribute					
IADL	Telephone			Y		
	Shopping	Y				
	Food	Y				Y
	Laundry					
	Transportation	Y				
	Finances					
Cognitive function	Learning and memory				Y	
	Language	Y		Y		Y
	Executive function	Y		Y		Y
	Complex attention	Y		Y		Y
	Perceptual-motor	Y			Y	Y
	Cognition	Y	Y	Y	Y	Y
Domain	Enjoyable/leisure	Y	Y		Y	
	Look after house					
	Hobbies/interests				Y	
	Mentally active	Y				Y
	Social/community	Y		Y		Y
	Distance (knn)	-	2	5	3	8

of attributes that match. This knn distance calculation is included in Table 3 as 'Distance (knn)'.

Results from this calculation allow the candidate MAs to be ordered by their closeness to the lost MA by using the Distance (knn) result: Having friends visit for lunch (8, closest match); video meeting with friends (5); gardening outdoors (3); being outside (2, most distant match).

The most closely matching MAs are presented to the PLWD as candidate replacement activities. Once the PLWD selects a replacement MA, the attributes of this MA are compared with the original lost MA to determine if any attributes remain unfulfilled. Assuming that the PLWD selects the most closely matching candidate MA from the example set in Table 3, 'Having friends visit for lunch', does not necessarily fulfil the shopping IADL (although it may do and this can be established), the use of transportation, and may not qualify as an activity in the enjoyable/leisure domain. It should be ensured that these specific activities

continue, either by the addition of a second new MA (in the set in Table 3 for example, 'being outside' can fulfil the 'enjoyable/leisure' domain) or setting goals to exercise specific IADLs (in the example set in Table 3, use of transportation may need to be explicitly exercised). Figure 1 shows the complete workflow to be implemented.

IV. DISCUSSION

In order to record achievement of activities, data on achievement of activities must be captured. This can be done by using sensors, with little or no demand on the PLWD, or by active self-reporting of activity data by the PLWD or their informal carer. We believe that of the 12 ADL and IADL activities, seven can be monitored by use of sensors, e.g. the 'bathing' ADL can be detected by use of capacitive humidity sensors and resistance temperature sensors in the bathroom and analysing the output from the sensors to detect use of the bathroom. We are developing techniques for performing this event detection, leaving five activities that will require self-reporting (i.e. manual entry of data into the app) of achievement of activities by the PLWD (e.g. completion of a 'shopping' activity). Table 4 summarises which ADLs and IADLs can be monitored by use of sensors and which require to be self-reported. 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 assistive tool, and our early feedback from carers is that this will be so. 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.

In order to design useful and usable technologies that will be used by PLWDs to support and maintain independence, it is necessary to understand their point of view and lived experience, without focusing solely on impairments commonly associated with dementia [36]. It is also important to note that personal, social, and environmental factors as well as a PLWD's specific disabilities result in needs, wishes and abilities which can vary significantly [39]. Involving end

TABLE 4. MONITORING METHODS FOR ADLS AND IADLS

Activity group	Activity	Monitoring method
ADL	Bathing	Sensors
	Dressing	Sensors
	Toileting	Sensors
	Transferring	Self-reporting
	Continence	Self-reporting
	Feeding	Sensors
IADL	Telephone	Sensors
	Shopping	Self-reporting
	Food	Sensors
	Laundry	Sensors
	Transportation	Self-reporting
	Finances	Self-reporting

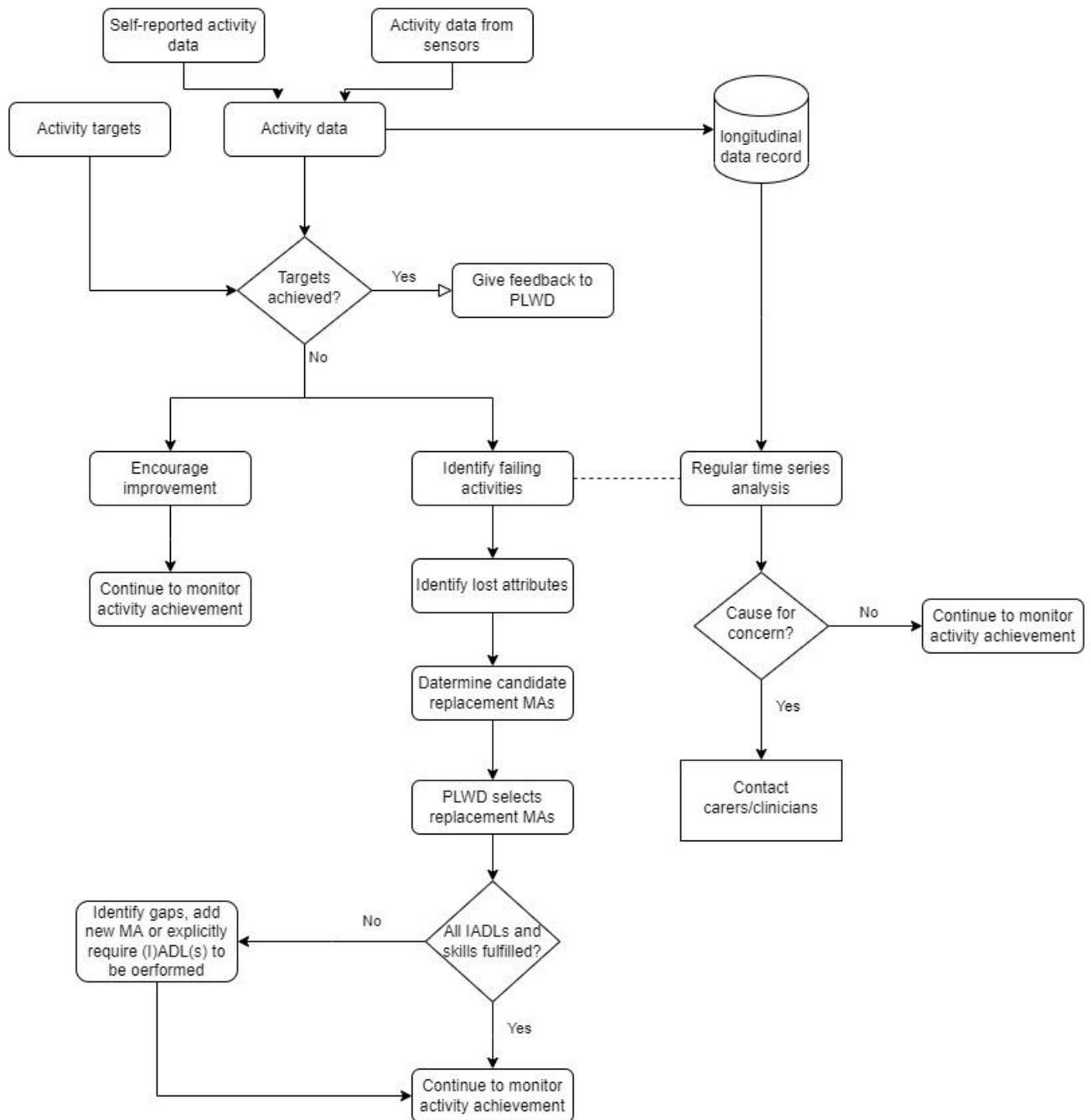


Figure 1. Workflow to capture activity data and suggest alternative activities

users considers the likely gulf between the day-to-day lives and life experiences of designers or researchers and PLWDs. Moreover, involving PLWDs in the design process can improve usefulness and acceptability of assistive technologies while also resulting in feelings of empowerment [40]. Being given a voice in this manner has led to designs that improve social interaction [41] and help to maintain independence through support for ADLs [42].

Mobile technologies and applications that allow for customisation can adapt and respond to the needs of individual users, which is considered particularly important for the developing needs of PLWDs in terms of cognitive deterioration and gradual decline in abilities [43; 44]. Among the themes to emerge from work carried out by Lindsay et al. [36] was the importance of a design feeling personal to the individual PLWD (due to the degree to which individual circumstances vary), while also integrating into the person's routine. Such factors were deemed crucial to determining whether a new device would be accepted. This can be achieved by taking an approach that focusses on a personally tailored design that considers an individual's day-to-to experiences, and the way routine is used to cope with daily challenges. Adopting this design approach, developing a relationship between the designer and the participant, and creating individually tailored prototypes thereby allows for a scenario where participants can focus on individual problems and get a feel for what a design that works for them specifically may look and feel like [40].

There is some literature on behaviour change, such as the work of Fogg et al. [45], Oinas-Kukkonen [46], Reimer et al. [47] and Webb et al. [48], which will inform our work on assisting PLWDs 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 [49], in particular because we are aiming at maintaining activities of PLWDs rather than changing them.

The success of our system will be measured by recording the period of independent living of our participant PLWDs against current established times for independent living following diagnosis with a dementing illness, the rate of decline in performing activities, and the 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, those that are specific, and from care plans. Additional goals can be included following discussion at co-design workshops and interviews with individual PLWDs. Goal targets can be determined from care plans, from existing achievement

levels of PLWD and their activity achievement ambitions. In this work we are focusing on the using the standard ADLs [22] and IADLs [23], activities recommended by clinicians derived from formal care plans, and MAs selected by the PLWDs. 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.

Goals and goal achievements are formally specified in conjunction with PLWDs. The set of IADLs is taken from Lawton-Brody [23], with achievement goals set in collaboration with PLWDs. Activities and goals from formal care plans are those specified for each individual PLWD. The MAs and goal targets are those specified by individual PLWDs. When performance of an MA has declined such that it is no longer being performed, replacement MAs are suggested using a simple knn approach that aims to ensure that the benefits of performing the lost MA are maintained, in particular the cognitive functions, the domains of pleasure or meaning, and the exercising of the IADLs.

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 of activity tracking on the PLWDs and their carers.

ACKNOWLEDGMENT

This material is based on works supported by the Science Foundation Ireland under Grant No. 19/FFP/6917.

REFERENCES

- [1] J. Turner et al., "A Goal-Driven Framework for Individualised Self-Care for Early-Stage Dementia," HEALTHINFO 2021: The Sixth International Conference on Informatics and Assistive Technologies for Health-Care, Medical Support and Wellbeing. IARIA, Oct 2021, ISSN: 2519-8491, ISBN: 978-1-61208-916-4.
- [2] World Health Organization. *Dementia*. [Online]. Available from: <https://www.who.int/news-room/fact-sheets/detail/dementia>
- [3] Health Service Executive. *Types of Dementia*. [Online]. Available from: <https://www.understandtogether.ie/about-dementia/what-is-dementia/types-of-dementia/>
- [4] G. Rakesh, S. T. Szabo, G. S. Alexopoulos, and A. S. Zannas, "Strategies for dementia prevention: latest evidence and implications," *Therapeutic Advances in Chronic Diseases*, vol. 8, pp. 121-136, Aug. 2017, doi:10.1177/2040622317712442.

- [5] M. Prince, A. Comas-Herrera, M. Knapp, M. Guerchet, and M. Karagiannidou. *World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future*. [Online]. Available from: <https://www.alzint.org/u/WorldAlzheimerReport2016.pdf>
- [6] M. Pinquart and S. Sörensen, "Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis," *Psychology and Aging*, vol. 18, pp. 250-267, Jun. 2003, doi:10.1037/0882-7974.18.2.250.
- [7] M. Prince, A. Wimo, M. Guerchet, G-C. Ali, Y-T. Wu, and M. Prina. *World Alzheimer Report 2015 - The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. [Online]. Available from: <https://www.alzint.org/u/WorldAlzheimerReport2015.pdf>
- [8] C. Olsen et al., "Differences in quality of life in home-dwelling persons and nursing home residents with dementia - a cross-sectional study," *BMC Geriatrics*, vol. 16, Jul. 2016, doi:10.1186/s12877-016-0312-4.
- [9] Department of Health. *The Irish National Dementia Strategy*. [Online]. Available from: <https://www.hse.ie/eng/about/who/healthwellbeing/healthy-ireland/publications/irish-dementia-strategy-1-.pdf>
- [10] NetwellCASALA. *Smart Dementia Care*. [Online]. Available from: <https://www.netwellcasala.org/smart-dementia-care/>
- [11] D. Edvardsson, D. Fetherstonhaugh, and R. Nay. "Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff," *Journal of Clinical Nursing*, vol. 19, pp. 2611-2618, Sep. 2010, doi:10.1111/j.1365-2702.2009.03143.x.
- [12] S. Donnelly, M. O'Brien, E. Begley, and J. Brennan, "I'd prefer to stay at home but I don't have a choice: Meeting Older People's Preference for Care: Policy, but what about practice?" Dublin: University College Dublin. School of Social Policy, Social Work and Social Justice, Jun. 2016, doi: 10.13140/RG.2.2.29520.61443
- [13] D. Carter. *Fix Dementia Care: Homecare*. [Online]. Available from: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_homecare_report.pdf
- [14] S. Evans, S. Waller, J. Bray, and T. Atkinson, "Making homes more dementia-friendly through the use of aids and adaptations," *Healthcare*, vol. 7, Mar. 2019, doi: 10.3390/healthcare7010043.
- [15] Department of Health. *The Irish national dementia strategy*. [Online]. Available from: <https://health.old.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>
- [16] L. Clare et al., "Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial)," *International Journal of Geriatric Psychiatry*, vol. 34, pp. 709-721, May 2019, doi:10.3310/hta23100.
- [17] L. Clare, "Rehabilitation for people living with dementia: a practical framework of positive support," *PLoS Medicine*, vol. 14, Mar. 2017, doi:10.1371/journal.pmed.1002245.
- [18] L. Clare et al., "Goal-oriented cognitive rehabilitation in early-stage dementia: study protocol for a multi-centre single-blind randomised controlled trial (GREAT)," *Trials*, vol. 27, pp. 152-165, May 2013, doi:10.1186/1745-6215-14-152.
- [19] T. J. Kiresuk and R. E. Sherman, "Goal attainment scaling: A general method for evaluating comprehensive community mental health programs," *Community Mental Health Journal*, vol. 4, pp. 443-53, Dec. 1968, doi:10.1007/BF01530764.
- [20] L. Stokes-Turner. *Goal Attainment Scaling (GAS) in Rehabilitation. A practical guide*. [Online]. Available from <https://www.kcl.ac.uk/cicelysaunders/attachments/Tools-GAS-Practical-Guide.pdf>
- [21] A. Phinney, H. Chaudhury, and D. L. O'Connor, "Doing as much as I can do: the meaning of activity for people with dementia," *Aging & Mental Health*, vol. 11, pp. 384-93, Jul. 2007, doi:10.1080/13607860601086470.
- [22] S. Katz, A. B. Ford, R. W. Moskowitz, B. A. Jackson, and M. W. Jaffe, "Studies of illness in the aged. The Index of ADL: a standardized measure of biological and psychosocial function," *JAMA*, vol. 185, pp. 914-919, Sep. 1963, doi:10.1001/jama.1963.03060120024016.
- [23] M. P. Lawton and E. M. Brody, "Assessment of older people: Self-maintaining and instrumental activities of daily living," *The Gerontologist*, vol. 9, pp. 179-186, Sep. 1969, doi:10.1093/geront/9.3_Part_1.179.
- [24] I. P. Donald, "Development of a modified Winchester disability scale--the elderly at risk rating scale," *Journal of Epidemiology and Community Health*, vol. 51, pp. 558-563, Oct. 1997, doi:10.1136/jech.51.5.558.
- [25] J. Burt, J. Rick, T. Blakeman, J. Protheroe, M. Roland, and P. Bower, "Care plans and care planning in long-term conditions: a conceptual model," *Primary Health Care Research and Development*, vol. 15, pp. 342-354, Oct. 2014, doi:10.1017/S1463423613000327.
- [26] Alzheimer's Association. *Daily Care Plan*. [Online]. Available from: <https://www.alz.org/help-support/caregiving/daily-care/daily-care-plan>
- [27] J. Diggs, "Activity Theory of Aging," in *Encyclopedia of Aging and Public Health*, S. Loue & M. Sajatovic, Eds, New York: Springer, pp. 79-81, 2008.
- [28] C. Barton, R. Ketelle, J. Merrilees, and B. Miller, "Non-pharmacological management of behavioral symptoms in frontotemporal and other dementias," *Current Neurology and Neuroscience Reports*, vol. 16, pp. 1-8, Jan. 2016, doi:10.1007/s11910-015-0618-1.
- [29] F. Mahoney and D. Barthel, "Functional evaluation: the Barthel Index," *Maryland State Medical Journal*, vol. 14, pp. 61-65, Feb. 1965, doi:10.1037/t02366-000.
- [30] NHS South East Clinical Delivery and Networks. *Dementia Care and Support Planning Generic Toolkit*. [Online]. Available from: <https://www.southeastclinicalnetworks.nhs.uk/dementia-csplanning-toolkit/>
- [31] L. Teri and R. G. Logsdon, "Identifying pleasant activities for Alzheimer's disease patients: the pleasant events schedule-AD," *The Gerontologist*, vol. 31, pp. 124-7, Feb 1991, doi:10.1093/GERONT/31.1.124.
- [32] S. C. Smith et al., "Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology," *Health Technology Assessment (Winchester, England)*, vol. 9, pp. 1-93, Mar. 2005, doi:10.3310/hta9100.
- [33] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*, Arlington: American Psychiatric Association, pp. 593-595, 2013.
- [34] R. Tuijt, P. Leung, E. Profyri, and V. Orgeta, "Development and preliminary validation of the Meaningful and Enjoyable Activities Scale (MEAS) in mild dementia," *International Journal of Geriatric Psychiatry*, vol. 35, pp. 944-952, May 2020, doi:10.1002/gps.5316.
- [35] T. Cohen and D. Widdows, "Geometric Representations in Biomedical Informatics: Applications in Automated Text Analysis," in *Methods in Biomedical Informatics*, I. N. Sarkar, Ed., London: Academic Press, pp. 99-139, 2014.
- [36] S. Lindsay, D. Jackson, C. Ladha, K. Ladha, K. Brittain, and P. Olivier, "Empathy, participatory design and people with

- dementia,” CHI 2012: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, May 2012, pp. 521-530, doi:10.1145/2207676.2207749.
- [37] F. J. M. Meiland et al., “Usability of a new electronic assistive device for community-dwelling persons with mild dementia,” *Aging and Mental Health*, vol. 16, pp. 594-591, Feb. 2012, doi: 10.1080/13607863.2011.651433.
- [38] Y. Kerkhof et al., “User-participatory development of FindMyApps; a tool to help people with mild dementia find supportive apps for self-management and meaningful activities,” *Digital Health*, vol. 26, Mar. 2019, doi:10.1177/2055207618822942.
- [39] R. M. Dröes et al., “Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice,” *Aging & Mental Health*, vol. 21, pp.4-17, Nov. 2016, doi:10.1080/13607863.2016.1254596.
- [40] M. Span, M. Hettinga, M. Vernooij-Dassen, J. Eefsting, and C. Smits, “Involving people with dementia in the development of supportive IT applications: A systematic review,” *Ageing Research Reviews*, vol. 12, pp. 535-551, Mar. 2013, doi:10.1016/j.arr.2013.01.002.
- [41] M. Morris, J. Lundell, and E. Dishman, “Catalyzing social interaction with ubiquitous computing: A needs assessment of elders coping with cognitive decline,” CHI '04 Extended Abstracts on Human Factors in Computing Systems, New York: ACM, Apr. 2004, pp.1151-1154, doi:10.1145/985921.986011.
- [42] J. Hoey, T. Pltz, D. Jackson, A. Monk, C. Pham, and P. Olivier, “Rapid specification and automated generation of prompting systems to assist people with dementia,” *Pervasive and Mobile Computing*, vol. 7, pp. 299-318, Jan. 2011, doi:10.1016/j.pmcj.2010.11.007.
- [43] A. J. Astell, B. Malone, G. Williams, F. Hwang, and M. P. Ellis, “Leveraging everyday technology for people living with dementia: A case study,” *Journal of Assistive Technologies*, vol. 8, pp. 164-176, Dec. 2014, doi:10.1108/JAT-01-2014-0004.
- [44] P. Jodrell and A. J. Astell, “Studies involving people with dementia and touchscreen technology: A literature review,” *JMIR Rehabilitation and Assistive Technologies*, vol. 3, Nov. 2016, doi:10.2196/rehab.5788.
- [45] B. Fogg and J. Hreha, “Behavior wizard: A method for matching target behaviors with solutions,” *PERSUASIVE'10: Proceedings of the 5th international conference on Persuasive Technology*, Jun. 2010, pp. 117–131, doi:10.1007/978-3-642-13226-1_13.
- [46] H. Oinas-Kukkonen, “Behavior change support systems: The next frontier for Web science,” *PERSUASIVE'10: Proceedings of the 5th international conference on Persuasive Technology*, Jun. 2010, pp. 4-14, doi: 10.1007/978-3-642-13226-1_3.
- [47] U. Reimer, E. Maier, and T. Ulmer, “A Self-Learning Application Framework for Behavioral Change Support,” *Information and Communication Technologies for Ageing Well and e-Health Second International Conference, ICT4AWE*, Apr. 2016, pp. 119-139, doi:10.1007/978-3-319-62704-5_8.
- [48] T. L. Webb, J. Joseph, L. Yardley, and S. Michie, “Using the internet to promote health behavior change: A systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy,” *Journal of Medical Internet Research*, vol. 12, Feb. 2010, doi:10.2196/jmir.1376.
- [49] J. O. Prochaska and W. F. Velicer, “The transtheoretical model of health behavior change,” *American Journal of Health Promotion*, vol. 12, pp. 38–48, Sep.-Oct. 1997, doi: 10.4278/0890-1171-12.1.38.