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Informal carer role in the personalisation of assistive solutions connected to aspirations of people with dementia

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Abstract. The increase in the elderly population over the last thirty years with consequent increase in the number of people living with dementia (PwD) has resulted in a research focus on improving quality-of-life and well-being beyond basic needs, to address psychosocial needs and to provide technological support for these. As part of a UK industry-led, publically supported, project Connecting Assistive Solutions to Aspirations (CASA), research is being conducted to inform the design of assistive technology packages that are aspiration-led. Focus groups were conducted with informal carers (family relatives) of persons with dementia to elicit views on technology use for increasing independence of PwD (with a carer living at home). The focus groups were analysed through thematic analysis and the results have been used to produce personas and scenarios for creation of demonstrator assisted living packages.

Keywords: Assistive Technologies, Telecare, Ambient Assisted Living, User experience, Dementia

1 Background

The ageing global population has led to increased prevalence of chronic diseases that cause functional impairment and consequent disability. Dementia, a syndrome of progressive decline of the brain and its abilities, including memory and cognitive functions, can greatly impact on independence and autonomy. At present, the number of people with dementia is doubling every 20 years, and in 2013 among there were overall 44.4 million people with dementia (PwD) in the world (62% living in developing countries)[1]. As part of the ‘Dementia Challenge’, the UK government has committed increasing funding for research and several new feasibility projects have been funded by the Technology Strategy Board (TSB) via the industry-led Small Business Research Initiative (SBRI), through a funding competition 'Long-term care revolution'. The TSB projects include CASA (Connecting Assistive Solutions to Aspirations), a commercial/academic partnership which will develop an aspiration-led approach and produce assistive technological solutions to support increased independence and autonomy in two populations: older people (including PwD and their carers) and young adults (school leavers) with complex learning difficulties, emotional, behavioural and communication difficulties, and autism spectrum disorders. The authors' contribution to CASA is primarily in relation to carers of PwD.

A focus on technological solutions for PwD in particular has developed within the more general area of assistive technologies and telecare for older people. A review of assistive technologies (AT) and services for PwD in the UK by Gibson et al. produced a useful taxonomy with three types: AT used '<u>by</u>', '<u>with</u>' and '<u>on</u>' PwD [2]. Technology used 'by' PwD includes clocks and signage, reminders, communication aids, furniture and daily living aids, and alerts/alarms. Technology used 'with' PwD includes reminiscence devices, games/puzzles and communications aids (such as books and cards). Technologies used 'on' PwD are telecare monitoring systems and devices such as fall detectors. This typology of AT is helpful in portraying a spectrum of autonomy for PwD in relation to technology. Much of the AT used 'by' and 'on' PwD is also found in the generational taxonomy of telecare whereby 1st generation is typified by alarms, 2nd generation by home sensors and monitors, and 3rd generation telecare, much less prevalent in current provision, by contemporary information and communication technologies (ICT) on a variety of digital platforms.

Much of traditional AT addresses physiological need and safety. However, in our approach to design and evaluation of AT connected to aspirations in gerontology we and others have found the Maslow Hierarchy of Needs to be useful [3]. According to Maslow different levels of needs are motivational drivers of decision-making processes. Lower level functional drivers include physiological needs (e.g., need to eat, drink etc.) but the higher levels of social needs, self-esteem and self-actualisation are more closely linked to aspirations. Aspirations are also described as personal goals in life that push people to achieve one or more needs in different ways in tune with a person's knowledge and beliefs [4], are strongly associated to personal well-being [5], [6] and can be fully achieved only when the need of autonomy, intended as self-determination, independence, freedom of choice and action are satisfied [7].

Federici *et al.* have drawn on a 'biopsychosocial' approach to the design and evaluation of AT aimed at addressing psychological and social as well as biological or medical needs [8]. Evidence already suggests that for older people including PwD, identity, stigma and choice are important factors in the acceptance of AT (such as telecare) [9]. This work has concluded that since telecare can both create stigma and protect identities, there may be a trade-off between how a product looks and how it makes people feel versus how it can enable them to live independently. Future telecare devices therefore need to be redesigned or repackaged to make them desirable.

In a world of ubiquitous computing that we are increasingly exposed to, more people are becoming more competent in choosing and operating technology packages that include mobile, PC or entertainment systems in and outside the home environment. While PwD may have difficulty installing or using them, carers may usefully employ non-traditional AT e.g. a tablet PC with apps that provide digital versions of traditional AT e.g., calendars, notes and lists, alerts etc. This can then support remote telecare (including telepresence) through networking and multimedia capability [10]. One vision of future AT packages as conceived by the CASA project is thus much closer to the provision of personalised consumer product packages, with a stronger link to lifestyle and a flexible modular configuration that adapts to requirements over time, for both PwD and their carer(s).

2 Methods and study design

In line with Human Computer Interaction (HCI) research in the area [11] the best way to appropriately design or modify and integrate technologies for people with disabilities or difficulties is to deeply understand the person's motivations, how they currently use technological tools, and how they will use future technologies. Tools to support design and evaluation include scenarios and personas and these are particularly useful when linked to a participatory design approach where users are involved in the process at early stage and preferably throughout the design process [12], [13], [14]. Personas can be used to rarify individual aspirations that new technology packages could support and scenario-based tools support designers with reliable examples of use during their development. Figure 1 shows a model for informing aspiration-led selection of technologies according to a user-centred approach.

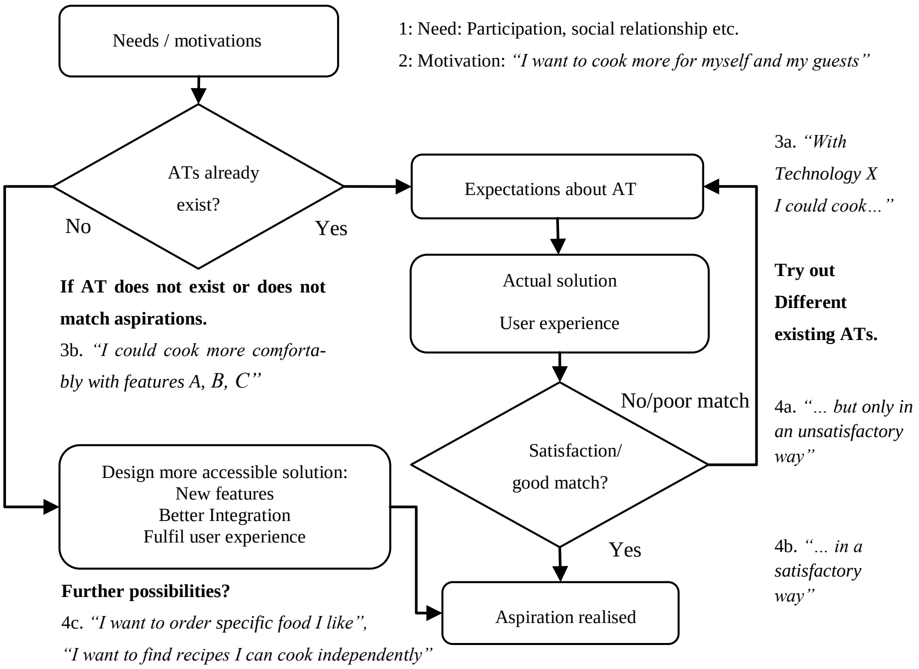

Figure 1. Model of aspiration-led evaluation and design

The main focus of the study was to elicit informal carer opinion about household technologies and AT to build plausible personas and scenarios to be used in later work involving creation of technology packages aimed at supporting PwD in daily living activities. Focus groups were arranged with a convenience sample of carers recruited through the Alzheimer's Society, Nottingham branch. For a short feasibility project (9 months funding), primarily due to ethical approval time constraints, it was decided not to involve PwD directly, with the caveat that PwD and carers may provide different and potentially conflicting perspectives so care must be taken to guide respondents so they consider desires of the PwD as well as the problems faced by the PwD and carer(s), and also encourage them to think more broadly about existing and potential technology support beyond that of traditional AT so as to avoid concentrating only on safety.

Ethical approval was obtained from the University of Nottingham Medical School Ethics Committee and an Alzheimer's Society Research Partnership form was completed with the Nottingham branch who agreed to recruit volunteer carers from the local community. Carers were given project information and completed a consent form, and reimbursement was offered for travel expenses and sitting allowances. The carer focus groups were audio recorded and field notes taken for thematic analysis.

Two focus groups were run involving three male (L., F., Z.) and three female (W., H., T.) informal carers participating overall who were all family relatives including: spouses (carer for their husband or wife at home); a son (secondary carer to his mother who was caring for her husband in their home); a brother (carer for his younger brother in the same home); a mother caring for her daughter at home, with secondary care from the daughter's sister-in-law. The carers were aged from 52 to 83 and the PwD from 55 to 86 having a variety of dementia types.

3 Results

Three main themes emerged during the discussion with the carers: i) Their feelings about dementia in relation to aspirations and technology; ii) PwD and carer stigma-related issues; iii) Technology and dementia - how technology could improve a PwD's independence, and the carers' opinions about the current and possible future technologies. Results within each theme are presented either as quotes or the gist of responses from several respondents.

3.1 Carer feelings about dementia, associated with technologies

Informal carers were strongly aware of their role in the decisions of PwD to use or disuse ATs. Carers in the groups had sometimes suggested new tools to PwD (e.g. picture cards to prompt self-care) and on other occasions had prevented or discouraged the use of ATs or other tools due to safety concerns or because the tool was too complicated to use by the PwD, the carer, or both. Also a generational issue was perceived in the use of technologies: *people with dementia and their relatives/carers (especially elderly people) do not accept using advanced technologies, or to ask for external support to help them use them.*

All of the interviewed carers believed that human prompting is more important than the technologies used. As H. suggested: "*We are the main AT ...*" Associated with that, carers underlined that the more an individual loses their autonomy with disease progression, the more carers also lose their independence and their social life. As Z. said, *"[it] can cause frustration and tiredness*."

As the carers underlined, a major consequence of dementia is the loss of independence perceived by their relative. As H. underlined, "*The diagnosis of dementia causes frustrations and depression ... In some cases the person is well-aware of they own status, and they can have suicidal thoughts… In particular, these feelings are caused by the awareness that they are not able to take care of themselves.*"

In discussion with the carers, examples of aspirations of the PwD in their care were to maintain or recover the ability to take their own decisions, cook for themselves or others (or select food items from the fridge), to answer and talk on the phone, to continue their hobbies or leisure activities (e.g. swimming) and maintain their relationships with friends. In tune with this result, any technology or set of integrated tools that could avoid or reduce the social isolation of PwD and support them in self-care, would be seen by carers as a very useful solution.

3.2 Stigma

The carers in this study underlined several issues associated to stigma, reporting that their relatives refused to use wearable technologies (such as a fall alarm). As T. suggested PwD *"... do not want that others to identify them as persons with a disease. However, sometimes they need other people to know that they have an issue, for instance when they behave in unexpected ways."* All the carers also agreed that stigma is one of the causes of self-imposed social isolation in PwD, due to a feeling of shame about their situation, or their being afraid of derision, or to be seen as dangerous people. Carers reported a reluctance to identify dementia as a disability on benefits forms or job applications. *A*s F. (and also L.) indicated, "*if asked to tick the option I prefer to not say*." All the carers agreed stigma could an important barrier to PwD using ATs and only an AT with good appearance, or with a design that looks similar to known (non-AT) technologies, would accepted and used.

3.3 Technology for independence

All the carers reported that PwD were familiar with lo- and hi-tech tools in everyday use. The most commonly used artefacts – by PwD autonomously or with the help of a carer – were found to be: telephone, TV, kitchen appliances, watches and alarms, paper and digital calendars, whiteboards, PCs and tablets. All the carers underlined that PwD would experience a rapid descent in individual functioning and gradually lose their previous capability to use existing artefacts. For example, all the carers reported that their relatives have had several issues in the use of telephone or mobile phones, such as problems in dialing or remembering how to unlock a mobile phone. Five of six carers said the PwD would appreciate tools such as "a *phone dialer system with pre-memorised numbers*" that could be used to make a quick call in a stressful situation. Carers also reported experience of communication problems during telephone conversations. As W. said, *"People with advanced stages of dementia can experience problems putting sentences together when they speak over the phone."*

When PCs or tablets were available in the home environment, carers reported that these kind of advanced tools were rarely by the PwD but some carer found them useful to manage and organise daily routines for them e.g., appointments. As T. suggested tablets and apps could, in principle, be useful to "*manage daily routine with reduced text and powerful graphical presentations [...], for instance to organise a menu for the day or a shopping list.*" However, at present these kind of apps were not considered smart enough by the carers and suggested that PwD would forget to open the app, and would therefore need human prompting to use these systems effectively.

Entertainment tools, and in particular TV and radio were considered useful technologies to help PwD to exercise memory. Nevertheless, a decrease in the ability of PwD to focus attention was considered to lead to a reduction of use of media devices.

Among the common domestic technologies, all the carers agreed that the use of kitchen appliances was the most problematic for PwD for several reasons, including safety associated with the use of water boiling tools and the use of gas hobs. As W. suggested, *"The use of a gas hob could be dangerous"* since the PwD could forget the appliance was hot or to turn off the gas after cooking. Carers therefore usually cook for PwD, or with them. All the carers agreed that when PwD strongly express the aspiration to cook for themselves, microwaves to cook pre-assembled food was the most effective and safe solution. Overall, though, the opinion of carers was that PwD cannot easily cook autonomously. As T. suggested, "*they could experience issues with following instructions or they may not be fully aware of cooking time. Often they eat raw or overcooked meals. In the light of that, devices that can help them to handle the cooking procedure could be very useful.*"

Carers reported that for PwD the most effective domestic tools were simple artefacts such as calendars and message boards. These tools were placed in the house to help the PwD to remember routines and appointments and meal times. As H. suggested, *"it is useful to write notes in different colours. Colours assist people with dementia to easily discriminate and remind them the things to do." A*ll the carers suggested use of coloured indications and pictures in the house to help PwD to recognise spaces and to oriente themselves. Outside the home, all carers agreed about the usefulness of identification systems, such as bracelets containing personal data and carer contacts. Door opening systems (one with RFID keyfob, although with a night-operating PIN code reported as problematic) and an outdoor key-safe system (for carer access) were reported as being used.

In addition to domestic appliances and lo-tech technologies, several hi-tech systems and existing ATs were reported being used or suggested by carers: fall alarms, door sensors, a centrally control alert system, heat and smoke detectors and medication devices. As Z. said, *"hi-tech pill dispensers with an alarm which starts when a person has to take medications and stops when the medication is taken are amazing tools [...] after a while if they have not taken the pills, the central control can send a message*.**"** In general ATs and control systems were considered by informal carers to be important tools, especially when they were not present. In particular carers underlined that central control and remote control monitoring systems with an alarm and cameras could be useful when the main carer is a worker, or when PwD lives alone or with an elderly carer (assumed to be less capable with technologies). Global Positioning System (GPS) devices were consider to be potentially useful for tracking movement when the PwD was out of the house or at work, although concern was expressed about the visibility of such devices to others. As H. explained, *"Tracking technologies could be a reassurance, both for the carers and for people with dementia, especially if these technologies are well designed and wearable. Maybe the best thing is that these tools are invisible to other people."*

Carers reported that any kind of ATs or tools that could help PwD to avoid the social isolation and prompt their independence in daily tasks could be considered a *"real life changer."* Carers suggested smart tools, equipment and appliances that could identify if the user has a particular difficulty and react in personalised manner. One example was a 'smart hob' that could identify an individual and then support them in making their own meals, with the opinion that something like this could really change the life of both PwD and carers. Having recently purchased a Smart TV with voice control and camera, one carer speculated how it might be used for the individual in their care e.g. the PwD could control the TV better, and the carer could remotely check if they are safe, and communicate with them.

4 Conclusions

From a small convenience sample one must be wary about generalising but, as might be expected from carer groups, there was great focus on safety in and outside of the home and on things the PwD was not able to do. On the other hand a desire was expressed to help the individual in their care perform tasks more independently (that would also reduce effort for the carer) and to continue their hobbies and leisure activities or maintain social relationships. Carers stressed their role as a vital adjunct to assistive technologies. Carers revealed the use of a number of mainly lo-tech technologies in their households used as AT but were aware of or saw the potential for hi-tech devices that could be used as AT including some recently acquired e.g. Smart TV, and also had ideas for technologies not currently available.

Personas of informal carers were produced using the information and the opinions gathered, taking into account varying exposure to existing technologies and different roles in the care of PwD. The results are now being used to define scenarios. The idea of 'enabler packs', that was conceived jointly by the CASA partnership, is leading to the design of customisable technology packages aimed at carers to assist PwD with minimal support. Meal-making and leisure activity technology packages are being considered initially. The plausibility of scenarios and packages will first be explored using brochures prior to the production of actual packages, thus introducing a degree of co-production into the final package designs.

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