Usability of intelligent assistive technology used by people with dementia and their caregivers

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Abstract

Intelligent assistive technology with context-aware computing and artificial intelligence can be applied to assist a person with dementia and their caregivers with activities of daily living. This paper samples such technologies with a focus on current knowledge and practice concerning usability. We used a scoping study to address the objectives of the research. Our findings indicate that despite the importance of technology customization to individuals' needs and capabilities it is not commonly addressed in the literature. Furthermore, while researchers are aware of the concepts and aims of evaluating the usability of technology, they seem to face difficulties in assessing them.

Keywords

Activities of daily living, cognitive assistance, dementia, evaluation of usability, family caregivers, human-centered design, scoping survey, user experience

1 Introduction

Dementia is a neurocognitive disorder, typically chronic and progressive, characterized by impairments in cognitive functions such as memory, attention, orientation, and language [1, 2] to the extent that a *person with dementia* (PwD) is not able to independently complete *activities of daily living* (ADLs) [3]. *Personal* (pADLs) refer to basic physical needs such as dressing, toileting, bathing, and eating, while *instrumental* (iADLs) are essential for living independently in the community, such as preparing food, taking medication, and doing laundry[4]. The ICD-11 [1] identifies three *degrees of severity* of any type of dementia. In the *mild stage*, a PwD may live independently but requires supervision and/or support with iADLs, such as locating everyday objects, and handling finances. In the *moderate stage*, PwDs require support to function outside their home environment. They can accomplish only simple household tasks and experience difficulties with completing pADLs. In the *severe stage*, memory impairment becomes profound, though it varies by etiology. PwDs are fully dependent on others for pADLs and they often experience total disorientation in time and place.

One of the most common diseases in old age, dementia is recognized as one of the most costly and burdensome health conditions [2]. Statistics suggest that the growing global population of older adults diagnosed with dementia reached 44.4 million worldwide in 2013, with projections indicating an increase up to 135.5 million by 2050. Concern over the limited availability of family and professional caregivers for this rapidly growing population is intensifying (ibid.). As the population ages, the number of potential caregivers decreases, and those available often lack the key skills to provide the necessary level of care [5]. Furthermore, as family caregivers become more involved while struggling to balance other familial and social roles and responsibilities, they often experience negative consequences on their health, such as burden, anxiety, depression, isolation, and sleep deprivation [6]. Technological innovation, including advances in communications, robotics, and sensors, are perceived as promising to tackle these challenges [5]. Specifically, *assistive technology* (AT) refers to a broad range of devices and systems designed to maintain or enhance an individual's functioning related to cognition, communication, hearing, mobility, self-care and thereby promoting their health, well-being, inclusion, and participation [7]. AT is not designed to perform tasks on behalf of the user, but are specifically designed to monitor the activities of cognitively impaired users and provide appropriate assistance, thereby enhancing the likelihood of achieving desired behavioral outcomes [8]. A specific category of AT, *cognitive orthotics* [9] or *cognitive assistive technology* [10] is designed to assist with *cognitive* tasks. For instance, AT is employed to remind PwD to take medication or that their family member is visiting them next day [9, 10]. PwDs and their caregivers routinely use low-tech aids, such as medication pill organizers, schedules, and notes. They are being offered high-tech aids, such as *intelligent assistive technology* (IAT) that employs artificial intelligence to assess whether and when an appropriate reminder or procedural guidance is necessary for task completion [11, 12]. Additionally, IAT should be *contextually aware*: able to examine its environment, react to changes within it, and thus provide help *when needed* [11].

Human factors and *ergonomics* are scientific disciplines focused on studying the interactions between humans and other components of socio-technical systems [13]. The aim of designing such products and systems is to minimize human error and enhance human efficiency. One attempt at managing human factors analysis and human errors is through the development and deployment of measurement standards such as the *Human Readiness Levels* (HRL) scale (ibid.). HRL complements and

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supplements the *Technology Readiness Level* (TRL) scale, which captures the maturity of technology before and after its integration into a developing system [13, 14]: HRL emphasizes the readiness to develop technology for effective and safe *human* use, and it should capture human-related features of technology development [14]. Similarly to TRL, HRL scale is divided to nine stages: *basic research and development* of principles, concepts, and the application of human characteristics, performance, and behavior, along with guidelines incorporating human-centered requirements to enhance human performance and human-technology interactions (HRL 1…3); development and assessment of user interface design concepts and prototype simulations in *laboratory and real-world environments* (HRL 4…6); full-scale testing, verification, and deployment in an *operational environment* with representative users and system hardware and software (HRL 7… 8); and the final stage, where the system is actively used in the *operational environment* with systematic monitoring of human-system performance (HRL 9) [14]. HRL is closely linked to *user-centered design*, a framework for the design and development of new products or the assessment and evaluation of existing products that explicitly considers potential users' needs, wishes, and subjectively perceived limitations of the IAT [5, 9, 12].

Some key definitions from the ISO standard on ergonomics of human-system interaction [15] read: "3.13 *usability*: extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use. … 3.3 *effectiveness*: accuracy and completeness with which users achieve specified goals. … 3.4 *efficiency:* resources used in relation to the results achieved. Typical resources include time, human effort, costs, and materials." Further important aspects of usability include *user satisfaction*, the "extent to which the user's responses resulting from use meet the user's needs and expectations; how *accessible* a product, system, service, or environment is to individuals with diverse needs, characteristics, and capabilities is another element of usability". As examples of differences in terminology, see e.g. [16], where *utility* refers to whether the design provides features that users *need* and *usefulness* covers how pleasant and easy to use technology is (usability) and whether it does what users need (utility).

2 Methodology

This short survey covers only some of the findings of my ongoing more comprehensive review of topical IATs [17]. For this survey, the following research questions to explicate the coverage of *usability* will be addressed:

1. What is the maturity of IAT for human use (= its HRL)?
2. (How) do the developers take the *progression* of the disease into account?
3. How exactly is technology being assistive?
4. How is the usefulness and usability of the technology evaluated (if at all)?

Our scoping study maps key concepts, main sources, and types of evidence available for the domain targeted. For methodological transparency, we followed the PRISMA-ScS checklist [18]. Our search combines electronic database platforms (APA PsycInfo, Google Scholar, IEEEXplore, ProQuest, PubMed, Scopus, Web of Science, as well as the digital library facilities of the Universities of Vienna and Ljubljana) with hand searches of electronic journals and literature identified through literature readings. For this survey, we included original articles, conference proceedings, and PhD thesis; written in English; and published "within the last decade" (i.e., since 2013). To be covered, IATs further had to meet the following *inclusion* criteria: direct applicability to dementia care, focus on assisting with ADLs, PwD, and/or family caregiver as a user. We *excluded* IATs developed for the support of other (if related) disabilities, such as traumatic brain injuries; that could only be used by professional caregivers.

3 Findings

We illustrate our findings for each research question using the technologies: COACH [10, 11] and AWash [19] (targeted ADL: handwashing); DRESS [20] (getting dressed); ToiletHelp [21], (using a water toilet); and Smart Toothbrush [22] (brushing teeth). The pADLs supported by these IATs must be performed regularly to maintain the person's independence, health, and overall well-being. As dementia progresses, PwD becomes increasingly dependent on others to complete ADLs, affecting their family caregiver and society (cf. section 1).

3.1 Human Readiness Levels

We assigned aggregated HRL scores according to the groups introduced in section 1, with most of the surveyed technologies ranking at HRL 7…8: COACH, AWash, and ToiletHelp. This likely results from our choice of targeted content, as we aimed to focus on IATs close to HRL 9. We mapped DRESS and Smart Toothbrush to the HRL range 4…6, as the first is about developing and evaluating a prototype in preparation for in-home trials with PwDs, while for the second only preliminary laboratory testing was conducted with healthy individuals.

3.2 Different stages of Dementia

The IATs selected for this article are intended to provide targeted assistance for different stages of dementia. ToiletHelp is aimed to be used by PwD in the mild stage of dementia, COACH in moderate to severe stage, DRESS and Smart Toothbrush in severe stage, while for AWash we have not found any explicitly targeted stage of dementia. We found no evidence of technologies taking into account individual differences and needs of PwDs and their caregiver, consequently, we were not able to find such technology that would be able to *adapt* according to the actual severity of dementia as disease progresses (cf. section 3.3). Such *customization* is needed as cognitive functions progressively deteriorate, with fluctuations in rating occurring throughout the day or as the system would be used over periods ranging from weeks to months or even years [19, 20].

3.3 Notions of Assistance

Assistance involves *interacting*, with *prompting* being an interaction strategy that has become widely popular also in the context of IATs. Within our target domain, we found *audio* prompts to be most common as they are part of COACH, AWash, DRESS, and Smart Toothbrush. Such assistance should guide

PwD through the sequential steps of the activity by pre-recorded voice commands. *Visual* prompts include *videos* of steps of activities (COACH); *pictures* of correct clothing items (DRESS); use of different *lights* to attract attention to the appropriate use of an object (DRESS, Smart Toothbrush); and *texts* with instructions (ToiletHelp). DRESS consists of *motivational* prompts in the form of songs or videos favored by the PwD are meant for when a PwD should get stuck in an activity, and are configured by the family caregiver. COACH has options for *increasing levels of support*: low-guidance and high-guidance verbal prompts, video demonstrations, or placing a call to the caregiver. DRESS offers the choice of *continuous* mode, which includes chronological directions across all steps of an activity, and *independent* mode, in which no audio prompts are provided while the PwD is donning a shirt, and the caregiver should receive text messages on their device either when help is needed or dressing is completed. Nominal assistance provided by ToiletHelp consists of acknowledgment messages displayed to reassure the users they have completed every step of the activity; when the need is recognized, instructions are repeated. If a user should still fail, an alert informs the caregiver the PwD is having trouble, along with a reassurance message being displayed to the PwD.

The IATs we identified can help guide PwD through activities, but it is crucial to tailor such assistance to individual needs and adjust it as dementia progresses [20]. While there are cases where differing/increasing levels of assistance are provided by IATs [10, 11], such adjustment is not commonly documented in the literature. Despite its importance, our research indicates that there is also a lack of consistency in the terminology used to describe the adjustment of IATs to individual needs (e.g. customization, personalization, adjustment, adaptation).

3.4 Usability

The resources we analyzed indicate a dearth of commonly used standardized usability tests; out of the systems surveyed, only Awash was assessed using the System Usability Scale (SUS) questionnaire [21]. Instead, information about the usability of IATs is often gathered through user interviews [10, 11, 19, 20], observation, and performance testing [10, 11, 22, 20, 23].

In terms of *effectiveness*, COACH and AWash users were able to independently complete more steps of activity and engage less with caregivers while using IAT. Regarding *efficiency*, the developers of the Smart Toothbrush have estimated its battery life, while those of DRESS considered the final product's cost. In terms of *user satisfaction*, caregivers noted several benefits of DRESS, including validation of memory loss, empowerment of PwD, promoting privacy and dignity, and providing caregiver respite. ToiletHelp was reported to increase PwD's autonomy, boost self-esteem and dignity, and reduce the burden on caregivers. Participants rated AWash with a positive user experience. On the other hand, difficulties in using the technology were due to varying stages of dementia, visual and sensory perception issues, the need to change routines, and *affordability* issues [19]. Users expressed dissatisfaction with long delays between tasks and the frequency of prompts [10, 11, 22], while overlapping video and verbal messages used in ToiletHelp caused distraction. The acceptance of IAT largely depends on its *utility* and its unobtrusiveness, which can encourage more consistent use.

The current understanding of usability reflected in the literature indicates that even when researchers are aware of the related concepts and terminology and aim to assess them, they have difficulties in doing so with unified questionnaires or standardized testing procedures.

4 Relevance of Cognitive Science

The goal of the inter-disciplinarity of Cognitive Science is to address the question of *how does the mind work* – why we do the things we do, think the way we think, and how we perceive the world around us – by trying to understand and explain underlying mental processes and mechanisms of human behavior from the point of view of each discipline [24]. In user interfaces, *computational models of human behavior* are used to describe and capture our understanding of typical user actions, predict future actions, and guide users toward improving their actions [25]. These computations are typically based on *internal symbolic knowledge representations*, allowing a cognitive agent to manipulate symbols to gain information about the external world and determine how to act effectively – plan and perform actions, and achieve specific goals [26]. Evolutionary psychologists view the information processing architecture of the brain to consist of *adaptive problem-solving systems* that use information to adaptively regulate physiology and behavior. In this perspective, attention, learning, emotion, and motivation all play key roles in minds work and how we respond to our environments [27]. In particular, motivation can *guide* cognitive processes: When a PwD becomes fatigued, their motivation to continue activities declines. IATs can help by providing motivational prompts, such as favorite music or videos, which evoke emotional memories. This is but an example of how, cognitive science provides crucial insights into how users perceive, process, and interact with technology and consequently affects both, the improvement of designs and testing of usability and usefulness. It is a "bridge" between applied artificial intelligence and user experience.

One important objective of applied artificial intelligence is the development of cognitive orthotics, designed to *enhance* and *expand the user's cognitive abilities* [28]. It is not about technology imitating human abilities, but rather *extending* them. The key focus is the importance of creating systems that combine human and machine components in a way that maximizes their individual strengths taking into account ethics. To design successful cognitive orthotics, *interdisciplinary* teams are needed to unite relevant knowledge and perspectives of professionals (such as computer scientists, engineers, physicians, cognitive psychologists, and neuroscientists) together with stakeholders and users of technology (ibid.).

5 Limitations and Future Work

As technology advances rapidly, future research should explore a wider range of IATs using novel modalities and supporting more diverse ADLs. This limited study cannot form generalized statements about IAT usability for PwD and caregivers, as comparing specific ADLs is challenging due to variations in particular activity structure, cultural contexts, and dementia stages. We focused on a small subset of IATs addressing some pADLs, excluding those covering iADLs and multiple ADLs. [17] takes a step in this direction.

6 Conclusion

Dementia is becoming increasingly prevalent, posing a major societal, economic, and global health challenge. While extending the duration of PwD's stay in their private homes may be seen to help alleviate the strain on institutional settings, it in turn places a significant burden on family caregivers. While IATs are intended to enhance the independence of PwD and reduce the caregiver's burden, our literature review efforts suggest that usability aspects are not systematically assessed. This gap is also linked to current HRLs, which indicate that existing IATs are not fit for deployed use by PwD. Moreover, we find that IAT is often not designed to adapt to the progression of the disease, affecting its utility and usability. Heavy terminology such as *intelligent assistance* appears to be employed all too easily. Furthermore, practice in assessing and reporting usability appears to leave significant room for improvement.

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