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Key Factors for a Framework Supporting the Design, Provision, and Assessment of Assistive Technology for Dementia Care

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Abstract. Assistive technology (AT) products and services are increasingly used to support persons with dementia (PwD) and their caregivers, in terms of healthcare, safety, autonomy, leisure and social participation. Studies conducted in this area have tended to focus on usability engineering and AT acceptance, rather than on AT provision and follow-up plans. In other fields of disability, efforts have been made to integrate AT modeling frameworks into delivery practices, including the selection and assessment of AT over time. In the context of dementia, probably because of the relative novelty of the use of AT, only a few works have stressed the need for a comprehensive framework to guide users, practitioners and product developers in decision-making regarding the conception, evaluation and provision of AT. In this paper we provide preliminary guidance for the definition of such a framework. For doing so, first we review two existing AT models, chosen because of their applicability in the field of dementia: Hersh & Johnson's "Comprehensive Assistive Technology" model and Scherer and colleagues' "ICF core set for Matching Older Adult with Dementia and Technology". Then we discuss some implications of the use of AT models and frameworks for clinical practice, specifically their incorporation within the integrated care systems increasingly adopted worldwide. Subsequently, we propose a set of key factors that should be considered for building tools to support AT design, provision and assessment in the context of dementia: the progressive nature of the disease, the clinical heterogeneity observed among PwD and the subsequent need for personalized care plans, the dynamics of function allocation between PwD, AT and caregivers, and the role of fluctuating symptoms and preserved abilities in this population. Finally, we suggest some directions for further research in this field.

Keywords. Assistive technology, dementia, design, delivery, assessment, integrated care.

Introduction

Alzheimer's disease and related dementias are one of the most important causes of disability among older adults and a major predictor of nursing home placement in this

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population [1,2]. Dementia covers a group of symptoms including progressive cognitive and functional decline, challenging behaviors and other psychological manifestations (e.g., apathy, agitation, social withdrawal, or wandering), which place persons with dementia (PwD) at a high risk of disability and dependence. Due to dementia symptoms and common age-related health issues PwD have a wide variety of continuing care needs. Consequently, these persons may require different health and social services to support them in everyday life actions such as housework, handling medication, social interaction or behavior management [3]. These services may combine personal assistance and Assistive Technology (AT).

AT has the potential to promote autonomy, quality of life, social participation and aging in place for PwD. AT products and services can also meet several needs of formal and informal dementia caregivers. Indeed, a wide range of AT applications are either commercially available or under active development for these purposes (e.g., telecare services, health-monitoring systems, wandering technologies, memory support devices, social assistive robots) [4-6].

However, effective design, provision and assessment of AT for PwD still poses many challenges in terms of usability, acceptability, training needs, access to services, continuous follow-up, ethical and societal issues [7-8]. Moreover, with the increasing generalization of integrated care pathways in dementia, which focus on medical and social care coordination, multidisciplinary case management, common tools for screening, individualized service planning and periodic reassessment of the situation of PwD [9], an important question emerges: how can AT solutions be effectively incorporated within a global care plan that responds to the individual needs of each PwD?

In order to provide PwD with optimal care and support through AT, it is fundamental to move our focus away from mere technology development and user engineering issues to look at how AT can best be implemented within a holistic care plan. This implies defining a comprehensive framework to guide the design, procurement and subsequent evaluation of AT solutions for PwD, structured around a multidimensional assessment of user's needs. In other fields of disability, different frameworks for the delivery and outcome assessment of AT have been proposed and validated [10-11]. However, only a few works have addressed this issue in the context of dementia [11-12].

In this paper we provide preliminary guidance for the definition of such a framework. First, we review some advantages and limitations of two existing AT models chosen for their adequacy with the field of dementia. Second, motivated by the increasing maturity of integrated care pathways in many countries, we acknowledge the need to consider AT provision for PwD within a holistic care system and reflect on how AT modeling and assessment tools could help in this regard. Then, we review key factors linked to the dementia situation that should be emphasized by these tools to better respond to the needs of all stakeholders involved and suggest some directions for further research in this field, with the aim of synthesizing existing models and tools to create a versatile yet practical AT design, selection and assessment framework that can be easily put to use in different national and local contexts.

1. Assistive Technology Modeling Frameworks

AT modeling frameworks [10-12,17-18] can serve a *descriptive purpose* including the gathering, organization and analysis of data related to the person, context, activity domain and AT itself, which can be useful for AT selection and advisory processes, as well as a *predictive function* by allowing the identification of relevant features pertaining to AT adoption. Thus, some models are more oriented towards the selection of AT solutions whereas others are more focused on the assessment of AT outcomes at a single point in time or through repeated assessments. A few of them can also be used to support AT design [18]. Although several AT models and frameworks exist in the literature, for the sake of clarity we review only two of them that appear particularly suitable for dementia care.

1.1. Comprehensive Assistive Technology (CAT) Model

Hersh & Johnson's CAT model [18] is inspired from the Human Activity Assistive Technology (HAAT) Model proposed by Cook & Hussey [17] to improve the understanding of how AT can help to enhance human performance. It was developed in response to the need of widening the flexibility and applicability of a modeling framework for AT. A social model of disability and User-Centered Design approaches have both strongly influenced the CAT model, which can be best described as a biopsychosocial tool. It comprises four components: person, context, activities and AT, offering a detailed analysis for each of them. Some of its applications are: the identification of accessibility barriers; the analysis of existing AT solutions; the formulation of guidelines for AT design; end-user assessment, device provision and AT profile and outcome measurement over time.

The CAT model's flexibility and openness make it easily adaptable to the context of dementia care and to any integrated care plan. It provides a common language for users, medical and social care staff and AT designers, making it a highly valuable tool in a context in which many AT solutions are emerging, as is the case with dementia. It also offers a detailed description of factors related to AT, which can be of practical use for all stakeholders, covering activity specification (e.g., task and user requirements), design issues (e.g., design approach and technology selection), system technology (e.g., interfaces and technical performance) and end-user issues (e.g., ease and attractiveness of use, mode of use, training requirements and documentation). Currently, the major limitation of the CAT model is the unavailability of practical assessment tools, which limits the applicability of this model in a real-world context. Other frameworks such as the MOADT described below provide such tools and could thus be deemed more useful, but they have other important drawbacks that could be overcome by leveraging the strengths of the CAT, in particular its flexibility.

1.2. ICF core set for Matching Older Adult with Dementia and Technology (MOADT)

Based on the International Classification of Functioning, Disability, and Health (ICF) [19] and the Matching Person and Technology (MPT) Model [20], Scherer and colleagues [12] proposed an ICF core set for Matching Older Adult with Dementia

and Technology (MOADT). This model offers a unified language and framework to help determine the best match between a PwD and AT solutions. The ICF core set for disease and disability assessment of dementia particularly emphasizes activities and participation as well as personal and environmental factors. To make it more user-driven, the model integrates a self-evaluation of his/her own functioning by the user as well as his/her views and expectations regarding a particular assistive device using some screening tools from the MPT Model [20]. After conducting a multidimensional assessment of the situation of PwD, professionals from a Center for Technical Aid can use the MOADT to help select an AT device that matches the user's needs and preferences, provide it, conduct follow-up assessment and offer AT support.
Because it uses the international criteria of the ICF, this tool enables a standardized assessment and the sharing and comparison of data among different stakeholders and countries. However, it appears highly dependent on an ideal assessment context, which makes it difficult to use in diverse national and local environments. First, because it is based on the ICF, the MOADT is a complex model (e.g., highly structured training required, long administration time). Second, different countries often have their own multidimensional geriatric assessment methods, and the rigorousness of the MOADT can make it incompatible with such tools. Thus, we propose below a synthetic approach which would bring together the strengths of the MOADT and the CAT to create an accurate yet flexible and practical tool for the inclusion of AT in the personalized care plans of PwD.

2. Implications for Clinical Practice: AT and integrated Care

In order to effectively meet the needs of PwD, AT solutions must be incorporated within *personalized and multidimensional care plans*. More generally, integrated care pathways are being progressively adopted to improve social and healthcare plans for PwD (e.g., avoiding the duplication of information, repeated assessments for the patient, complex and long procedures…).

By including AT selection and assessment processes within a global integrated care system, practitioners could benefit from previously gathered data through standardized geriatric assessment tools to describe the basic factors of AT models (i.e., person, context, AT, activities) without the need to conduct repeated assessments. Moreover, AT adoption and AT outcome assessment over time can be effectively coupled with the periodic assessment of patient needs suggested by integrated care models.

Integrated care models could provide new perspectives for achieving a better AT service level because a general care plan will help to better allocate resources and solutions (personal and technological) to respond to each user's needs. Both, the CAT and the MOADT models offer a set of valuable tools that should be examined in regard with existing screening methods currently used in various integrated care systems for dementia across different national and local contexts. This exercise will allow the identification of the dimensions that are currently well informed by standardized procedures and of those for which a specific assessment tool should be built and validated, particularly with respect of AT specifications.

3. Key Factors to be considered in an AT Framework for Dementia Care

Through our clinical practice we have identified a number of factors that are particularly salient in the situation of PwD but not necessarily properly identified and taken into account by professionals dealing with AT (manufacturers, procurers, case managers…). We thus argue that these factors should constitute the primary focus of future practical tools geared towards these professionals, to maximize efficiency:

- The *progressive nature* of dementia and the wide *clinical heterogeneity* observed among PwD [13]. AT solutions need to be adaptive, flexible and highly customizable. In particular, people progressively become less and less able to learn how to operate new devices. Thus, providing ways to predict likely future AT needs before they become too critical should make it possible to procure AT devices at a time when users are still capable of learning how to use them.
- *Caregiving situation:* PwD increasingly rely on the support of others; most frequently on informal caregivers [14]. The integration of AT into the preexistent caregiving situation should be supported with tools to optimize function allocation (i.e., redistribution of tasks and efforts) between human and AT, depending on the user but also on the skills and preferences of the caregivers, which are rarely thoroughly examined.
- *Fluctuating symptoms* are observed in many PwD in terms of cognitive functioning, behavior, and arousal [15]. This highlights the need for the inclusion of at least some basic form of artificial intelligence in AT for PwD, in order to take into account day-to-day changes in their needs and capabilities and adapt accordingly.
- *Preserved abilities:* PwD retain some cognitive and psychological capacities throughout the course of the condition. Following a biopsychosocial approach, AT for PwD should be designed based upon the strengths and desires of the person and not upon his/her deficits, in order to stimulate the user and promote autonomous activity. Future tools should thus facilitate the identification of these strengths instead of focusing only on the deficits that need to be compensated for; the solution that yields the best long-term outcome might not be the one which provides the highest level of compensation but instead makes the most use of these preserved abilities.

4. Conclusions

A modeling framework for AT in the context of dementia could provide a structured method to examine different individual and contextual factors that may influence the acceptance of AT solutions, their effectiveness and their adoption. The two frameworks here described support the multidimensional assessment of users' profile and subsequent selection of adequate AT. The MOADT model by Scherer and colleagues has the advantage of being an ICF-compliant tool specifically conceived for dementia care. However, the CAT model by Hersh and Johnson appears more flexible to support different AT processes, in particular the identification of new areas of research for AT design. Future research in the field should consider the

examination and synthesis of these models in relation with the screening and intervention procedures recommended by integrated care models currently used in the field of dementia, with a focus on a few key factors that are not yet well understood by professionals in spite of their importance for PwD.

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