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This is a precis of the following paper :

The Person Living with Dementia, their Carer and their Digital Technology

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Abstract. An appropriate research framework is hypothesized in the context of software integral to ICT or assistive technology for people with dementia and their carers. The need for this is driven by the conclusion that literature reporting such technologies fail to adequately consider the carer role, skills and burden or clearly position the outputs in the context of readiness for use by others. The frame work draws on well-established frameworks but the steps are made appropriate to dyads,

Keywords. dementia, alzheimer's, carers, assistive, information, technology, computer, software, design, framework

Introduction

The research context of a highly variable population and concomitant complexity of appropriateness for AT solutions is introduced. It is noted that from state of the art knowledge on many aspects of dementias that it is not yet possible to precisely inform AT design for people living with dementia. The focus of the paper is, who the end users should be when designing for people living with dementia including carers. User centred design would suggest both. There are obvious scenarios where carer(s) overtly have a role as a user - as a facilitator or as a user in the identical way to the person with dementia. In all such cases there is a constant 'triad' of the person with dementia, their carer(s) and the technology. How well existing publications account for the role of carers is questioned.

The fundamentals of approaching design of AT for people with dementia is summarised highlighting the need for personalisation.

Methodology

The method employed was based in searching and reviewing appropriate literature from the last ten years. The details of which are summarised but these are the same as employed in another publication by the authors in the same book as this article. The difference came in extracting and analyzing data relating to reporting of the carer role and burden in the articles. If there was sufficient description the intent was to summarise this to make general inferences.

Results

612 different publications were found after elimination based on title and abstract, and then through reading the full papers only 24 aimed at people with dementia as direct users of the AT. Noting that of these 24, 5 only inferred from the work of others, a high proportion had clear involvement of people with dementia and their carers involved in design and evaluation (14 out of 19). However, there was only explicit information of the role and

workload for the carer in 2 articles; 17 gave some consideration to role but didn't provide information on this role. None considered the IT literacy of carers.

It was noted that the settings of the studies varied, most being in dementia day services, but the scope of activities was very varied.

Discussion

Consideration of people living with dementia and their carers has occurred in most instances in the reviewed literature. However, in most cases there was a distinct lack of information important to understand the skills and consequential burdens on carers. Also the specification and evaluations were not positioned in an innovation or design framework to allow appropriate interpretation of what stage of innovation and readiness for market had been achieved.

A proposal for a general framework user centred design of ICT products

A 12 step innovation or design framework to generate ICT AT products that are informed by user input is hypothesized. It ensures consideration of design/innovation loops that consider the person with dementia, their carer and the 'AT'. Its potential to be employed for an individual case or for groups/populations is noted.

The steps where risk, safety, ethics, essential and optional input from users, are all identified. Specific study or methodological tools are not stipulated as these can be left to the researchers/innovators to choose appropriately.

Discussion of considerations of involvement of end users and their carers is presented. The need for a period of getting to know them, and when appropriate separate investigation of goals and skills are highlighted. Process models for each 'user' in the dyad will be needed if their activities are different. It is recommended that both members of a dyad are considered with equal importance not least because of the progression of dementia.

The possibility that software implementations can be quite different and easily be made to be adaptable is mentioned to imply that this variability should be employed to respond to the needs of what is a heterogeneous population.

Conclusions

It is concluded that overly simplistic and therefore inadequate consideration of the role, skills and burden of carers in software aimed at people with dementia undermines their potential for uptake in care settings. The authors recommend the framework as an appropriate way for innovators in this field to improve their designs and reporting of outcomes to help inform uptake.

References

There are 9 references.

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