

Understanding the lived experiences of Mexican informal caregivers with Ambient Assisted Living Technologies

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Abstract. Ambient Assisted Living (AAL) Technologies, have the potential to support the people with dementia living in their homes for longer. Dementia is a major public health concern. It currently affects approximately 46.8 million people worldwide and by 2050 this figure will increase to 131.5 million. Low-and-middle income countries (LMIC) will be particularly affected by this situation as their poor health infrastructures and governmental support will mean that they have to rely on the informal caregiver (IC) sector. ICs are people who care for a dependent or disabled family member, commonly spouses or daughters. Mexico was the first Spanish speaking country in the world to recognise dementia as a public health priority. In-home technologies, such as AAL Technologies, are used in dementia care in order to improve patients' and caregivers' quality of life. This paper explores the way in which Mexican ICs of people with dementia (PWD) make sense of their lived experiences with AAL technologies.

Keywords: Ambient Assisted Living Technologies, Informal caregivers, Interpretative Phenomenological Analysis, Dementia, Mexico.

1 Introduction

Dementia is the term used to denote a set of symptoms caused by different diseases [1]. It implies an overall deterioration of mental functions, although one of its characteristic features is the loss of recent memory. Symptoms may include loss of language functions, inability to think and reason abstractly, or to take care of oneself, personality changes, emotional instability and loss of orientation in time, in person and in space. By 2050, it is estimated that Latin American countries such as Mexico and Brazil, will experience an increase of >400% in the number of dementia cases [2]. Alzheimer's Disease International [3] has stated that low-and-middle income countries (LMICs), such as Mexico, are not prepared for the imminent shift and the number of dementia cases. In 2015, 800,000 of Mexico's estimated population of 120 million, were reported to be living with some type of dementia [4]. This number is predicted to increase to 1.5 million by 2030 [3]. It has been argued that a significant shortage of geriatricians in Mexico is one of the reasons why family members are the main care providers in that country [5]. Additionally, due to the scarcity of nursing homes and the cultural stigma associated with institutionalized care, there is a dependency on ICs in Mexico [6]. Unfortunately, there is also a scarcity of literature about ICs in Mexico [7]. ICs are difficult

to understand as every PWD diagnosis story and circumstance is unique for any particular IC. For instance, the perception of an IC who is a spouse, will be different to the one who is a daughter, of the PWD. By exploring the accounts of ICs in Mexico, we expect to develop a deep understanding of the impact of the use of AAL technologies in their lives. This richer picture will allow an interpretation of several layers of their caregiving role, for instance, interpreting their needs, adoption barriers and technological requirements.

2 Research on Caregiving Experience with Ambient Assisted Living Technologies

Ambient Assisted Living (AAL) technologies are encompassing systems used in dementia care to facilitate the caregiving experience of PWD [8] [9]. AAL technologies (also classed as assistive technologies) are used for in-home care and can support ICs and PWD in varied ways such as: mobility, monitoring and safety [8] [10]. AAL technologies have been promoted as a potential solution to the global ageing crisis by the World Health Organization [11], who have asserted in agreement with the United Nations (UN), that every Member State from the UN, should provide access to assistive technologies, such as AAL, as a human right and prioritise international cooperation to find solutions to the ageing shift. In addition, they have also emphasised “*an urgent need to change the way we have traditionally perceived, designed, produced, manufactured, distributed, serviced and financed assistive products*” (ibid. p.1). The literature is limited in this area of research [12] [13]. As such, there is limited information to guide technology developers and designers about the particular needs of ICs of PWD to improve their caregiving experience.

It has been established that each IC’s account of their caregiving experience is unique since every PWD, and therefore their IC, reacts differently to the progression of the illness [1]. There is also limited information in the field of AAL technologies for in-home dementia care since it is an emerging area of study [13]. Few extant studies explore the caregiving experience of ICs of PWD and their use of technologies to facilitate their daily caregiving responsibilities, in particular, ICs from specific socio-cultural contexts [12] [14] [15]. ICs generally buy, manage and install AAL technologies for their PWD at home. This normally happens because as dementia progresses the patient can no longer make decisions by themselves, making them completely dependent of their IC [16]. As ICs are final users of AALs, they directly receive the information that these types of technologies provide [17]. Therefore, ICs’ perspectives are of great value as they can clarify what PWD and other ICs really need, thus helping to develop new technologies that will work for them especially within a particular cultural context. Mexico, for example, is a country with core cultural values that influence ICs’ caregiving experience [18]. Furthermore, technology adoption is linked to the ICs’ cultural background [19]. This suggests that the interventions developed for ICs and PWD should prioritise their designs to assist their cultural needs, in addition to activities of daily life [20].

Due to these related factors, research in the use of AAL technologies in informal dementia care is needed since both the expected demographic shift and rise in dementia

cases are imminent, especially in LMICs such as Mexico, where caregiving is predominantly provided by the informal care sector members of which have particular core cultural values that shape the way they perceive their experiences. This study aims to address these issues by studying the individual caregiving experiences of ICs of PWD, facilitated by AAL technologies. In particular, the study will examine how Mexican ICs of PWD make sense of their experiences with AAL technologies in their caregiving roles. No existing studies have examined the experiences of Mexican ICs who use AAL technologies to care for PWD at home.

The guiding research question for this paper is therefore: *How do Mexican informal caregivers of people with dementia make sense of their lived experiences with AAL technologies?*

3 Methodology

This study focuses on exploring the subjective experiences of ICs of PWD and perceptions of their use of AALs in their caring roles. In this project, the meaning caregivers place on AAL technologies is important because it represents their worldview, positive and negative feelings, perceived benefits and acceptance towards in-home care technology. Thus, a qualitative study using a phenomenological methodology was chosen for this investigation. As part of this research approach, a homogeneous purposive sample of 20 Mexican ICs between identified and selected from the databases of the Alzheimer's Association in Monterrey will be interviewed. The interview data will be analysed using an Interpretative Phenomenological Analysis (IPA) approach [21]. This approach enables the exploration of how participants make sense of their lived experiences from a subjective point of view [22]. This will allow for an in-depth individual account of their perspectives towards the use of AAL technologies for their caring role.

4 Expected Findings, Future Work and Conclusion

This study is the first of its kind and the findings will contribute to the extant literature by providing detailed individual accounts of the perspectives of ICs in the use of AAL technologies to care for PWD. Twelve interviews have been conducted to date from a sample of ICs associated with the Alzheimer's Association in Monterrey, Mexico. This self-selected sample is mainly made up of females between the ages of 45-60 of Mexican nationality acquired through birth, who have used an AAL at some point in their caring role with a family member with a type of dementia at home in the city of Monterrey, Nuevo Leon. Results from a preliminary review of the data hint at some interesting and some surprising findings. For example, one such unexpected finding was the fundamental role that faith and spirituality play in their mental wellbeing in their caregiving experiences. The following quotes reflect how some participants describe their faith as a source of strength during difficult times:

“If you don’t believe in God, then you can’t handle this. This illness. If it weren’t because of God’s hand, I wouldn’t survive it” (Participant 5).

“Oh wow! I don’t know. Without God there is nothing. Sometimes I look back and ask myself ‘How did you do it?’. It was only by God’s grace” (Participant 8).

“My faith, it is everything. All my work, it is because of my faith. I know God is expecting something from me...Maybe to help families in the future or ill people. There is a purpose behind this pain” (Participant 10).

Other preliminary findings are that: cameras are the most common technology used; the role of IC is traditionally taken by the eldest sister and males are not involved in the caregiving experience; people that can afford technologies are from an affluent or middle-income background; and families are generally not concerned about privacy issues related to monitoring a PWD. Further results will be presented at the time of the conference in the form of emergent themes. This project’s impact is more long term in that it may contribute to developers’ and designers’ understandings of the technological solutions for dementia care, since it will provide detailed profiles of an important stakeholder in this field, i.e., the ICs. In the future, this project could be expanded to other cultural contexts. In addition, a triangulation of diverse cultures and stakeholders using AAL technologies could be explored.

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