Assistive Technology and Dementia Caregiving: A Few Social Considerations and Policy Implications

Suzanne H. Hammad[1], Dena Al-Thani[2]
[1]Independent Research & Evaluations Consultant
Adjunct Lecturer of Sociology, Northwestern University Qatar
suzanne_hammad@yahoo.com
[2] Information and Computing Technology, College of Science and
Engineering, Hamad Bin Khalifa University, Doha, Qatar
dalthani@hbku.edu.qa

Abstract- With older persons increasingly wanting to age in familiar places, among community and family, their natural habitat, technological innovations greatly facilitate that. IATs are designed to ease the burden on families and healthcare systems while enhancing the quality of life and independent living of persons with dementia. This article questions the readiness of societies to accept the use of IAT with their older loved ones. It outlines some of the key social considerations that should be better understood in order to mitigate the barriers to AT use from an end-user and community perspective. It proposes policy interventions that could enhance the acceptance and use of IAT among older persons, taking into account sociocultural and prevailing attitudes, especially in Arab Muslim societies, while benefiting from global experiences.

1. Introduction

Due to the gradually disabling nature of the Alzheimers Disease and Related Dementias (ADRD), those affected will gradually lose their ability to carry out normal everyday tasks. These challenges are compounded by global trends of decreasing caregiver-to-patient ratios on the one hand, and financial and logistical challenges posed on national healthcare systems on the other (Ienca et. al, 2017; Prince et. al, 2015). With older persons increasingly wanting to age in familiar places, among community and family, their natural habitat, enabling older persons with ADRD to stay in their own homes for as long as possible is greatly facilitated by technological innovations (Diaz-Orueta & Konstantinidis, 2020). These are designed to ease the burden on families and healthcare systems while enhancing the quality of life and independent living of the persons living with the disease. According to the World Health Organization (WHO), over two billion people will need at least one assistive technology by 2050 due to ageing populations and associated increases in noncommunicable diseases (WHO, 2012). The question remains: how ready are societies to accept the use of IAT with their older loved one? What are the barriers that could influence the effective utilization of IAT in the field of dementa care? We conclude with recommended policy interventions that can be drawn and considered in future work in this area.

2. Social considerations pertaining to AT use in dementia care

ADRD does not occur in a vacuum. To be useful, relevant, we must better understand and address barriers from an end-user and community perspective. This entails taking into account social considerations and working holistically to address them or mitigate the barriers.

- The digital literacy divide: Despite the benefits of technology, there is a distinct 'digital divide' between generations that puts older persons at a greater disadvantage. It is important to point out that these disparities are magnified for older persons with cognitive impairments and reduced capacities such as ADRD. These disparities are often rooted in self-stigma or ageism which can limit older persons access and use of technology e.g. their own limited experience with ICT, attitudes toward ICT use, lack of confidence or functional limitations, among other personal factors (Rochleau, 2020; Hayden et al, 2012). The Covid-19 pandemic and increasing digital inequalities have put older generations in a more vulnerable position than ever before due to the added challenges of accessing important health information and online activities (Beaunoyera, et. al, 2020). According to a study by Dishman & Carillo (2016), further barriers to accepting the use of AT for older persons with ADRD in particular include: a) lack of awareness about the value of AT for their condition, b) assumptions that the use of AT requires skills they lack or need additional training courses, c) lack of preparedness among health and social care staff to incorporate IAT into their practice, and d) in some cases stigma and denial about the capacity of older persons to engage with ICT . A number of psychological factors also contribute to low interest among older persons in adopting new technologies. These include lack of knowledge and confidence, feelings of inadequacy, and comparison with younger generations, lack of social interaction and communication (Vaportzis et al., 2017; Delello and McWhorter, 2017). Levels of confidence among older persons in relation to technology will also differ across cultures, socioeconomic status, demographics, and gender: baby boomers more accustomed to hand-held devices will more readily accept and adapt to more sophisticated developments in IAT.

- Accessibility and affordability: According to World Health Organization (WHO), out of over a billion older persons globally who could potentially benefit from assistive technologies, only one in ten has access to them (WHO, 2017). Socioeconomic factors and access to equitable health services and technological advancements exacerbate the digital divide, with older persons and especially those with cognitive impairment the most likely to be left behind (Benett et. al, 2017). Lifetime cost of technology for persons with dementia was estimated at 200,000GBP per person across an average of 4.5 years from diagnosis to end of life (PIRU, 2017). Cost and access considerations should be addressed to avoid the risk that IAT adoption will be limited to 'those who can afford it' and lead to unintended societal consequences. To prevent this risk, integration of IATs for the aging population should be coordinated with health policy plans and health insurance (Ienca et. al, 2017).

- One size does not fit all: the need for further evidence: Persons with ADRD do not constitute one homogenous group; they have varying needs and varying symptoms across the stages of disease progression. This is while most,ATs tend to be targeting a vast and clinically heterogeneous end-user population including people with general neurocognitive disabilities (Diaz-Orueta & Konstantinidis, 2020). Future IATs should be adaptive to each specific form of dementia and their different stages and the specific needs of each end-user across the spectrum. Furthermore, sociocultural variations, differing public attitudes, caregiving structures and dynamics, knowledge levels (as well as languages) must be taken into account to maximize their acceptability

and adoption. In many contexts, there remains a weak evidence base on the lived experiences of persons with dementia, let alone access and use of technological innovation in dementia care. There is a lot to be done in terms of research especially in the Middle East region (WISH report; Kane et. al, in press).

- Resistance and stigma, community acceptance sociocultural beliefs and attitudes expectations: Older populations tend to perceive AT positively if it gives them a sense of efficacy for as long as possible and their ease of use, and similarly for caregivers, provided its role is seen as complementary rather than a replacement to formal health care, (Egan & Pot, 2016; Yusif et. al, 2016; PIRU,). However, some social attitudes inhibit their adoption especially in relation to persons with ADRD. The stigma associated with technologies that are marketed for people labeled as "dementia patients" or labeled as "gerontechnologies" has been argued to prevent their use (Yusif et. al, 2016). or being seen using AT in public, There is also the issue of stigma of resorting to the use of AT in some communities or being seen using it in public with their older loved one. In Arab Muslim communities, a strong sense of moral and religious responsibility to dedicate one's life to caregiving for the person with ADRD often limits help-seeking outside of the home (Hammad et. al, 2019). This could affect attitudes towards use of AT and warrants further research. Additionally, some professionals are reluctant to use IAT with their patients if they do not have enough knowledge about new technologies or reluctant to adopt due to lack of clinical validation of many of them (Egan & Pot, 2016; Diaz-Orueta & Konstantinidis, 2020).

- Shifting family dynamics and decreasing multi-generational living arrangements: Intergenerational living in the presence of extended families can be calming for older persons experiencing cognitive decline and also for the caregivers who find solace and reward in supporting their loved ones (Hammad et. al, 2019). However, migration patterns and rapid socioeconomic shifts have been affecting family dynamics and visibly decreasing multi-generational set ups. As a result, many older persons now live alone in different homes, cities, or countries. Those who live with family members are often left at home with a helper or nurse to enable the family caregiver to remain employed. These shifting family dynamics and reportedly smaller caregiver-person ratio calls for innovative solutions to promote safe mobility, independence, decision making, and monitoring and communication (Ienca et. al, 2017). The desire or necessity to remain connected is in fact one of the motivators pushing older persons to accept new technologies (Hasan & Linger, 2016).

3.   Policy implications and the way forward

Despite the barriers to societal acceptance and use of AT in dementia care outlined in this paper, IATs can provide older adults with ADRD and their caregivers significant assistance in managing their activities of daily living, preventing and managing risks, and to enhance their social environment and overall wellbeing. To address these social considerations, a systematic and multi-stakeholder approach must be taken whereby the needs and wellbeing of persons with ADRD and their caregivers and the societies in which they live are central to the design and dissemination plan of IAT (Barbarino et. al, 2020). This will require benefiting from global experiences and coordination of efforts through shared platforms to develop user-friendly clinically validated technologies, encourage more evidence-based research to guide developers and practitioners with an emphasis on qualitative insights from end-users, and the development of standardized measures and guidelines to determine the appropriate combination of eHealth

and other face-to-face care coupled with public awareness campaigns to encourage community acceptance and reduce stigma.

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