Featured Article

Ethical adoption: A new imperative in the development of technology for dementia

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Abstract

Introduction: Technology interventions are showing promise to assist persons with dementia and their carers. However, low adoption rates for these technologies and ethical considerations have impeded the realization of their full potential.

Methods: Building on recent evidence and an iterative framework development process, we propose the concept of "ethical adoption": the deep integration of ethical principles into the design, development, deployment, and usage of technology.

Results: Ethical adoption is founded on five pillars, supported by empirical evidence: (1) inclusive participatory design; (2) emotional alignment; (3) adoption modelling; (4) ethical standards assessment; and (5) education and training. To close the gap between adoption research, ethics and practice, we propose a set of 18 practical recommendations based on these ethical adoption pillars.

Discussion: Through the implementation of these recommendations, researchers and technology developers alike will benefit from evidence-informed guidance to ensure their solution is adopted in a way that maximizes the benefits to people with dementia and their carers while minimizing possible harm.

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Keywords: Dementia; Alzheimer; Technology; Ethics; Biomedical ethics; Technology adoption; Assistive technology; Technology development

1. Introduction

In recent years, there has been much interest in the use of technology solutions to assist with symptom management and maintenance or improvement in quality of life for older adults with dementia and their carers. Based on the current literature, seven broad overlapping categories of technology-based solutions are currently available: (1) cognitive aids [1,2]; (2) care robots [3]; (3) physiological sensors [4]; (4) environmental sensors [5]; (5) surveillance devices [6]; (6) cognitive engagement and monitoring systems [7]; and (7) integrated systems, which draw data from a network of heterogeneous inputs from the previous categories and apply artificial intelligence to provide supervision, guidance, and feedback to users [8,9].

Taken together, these technologies are promising in their potential to compensate for cognitive and physical limitations of persons with dementia, reduce carer burden, promote independence and autonomy, manage safety risks in the environment, and reduce stress. Nevertheless, despite these potential benefits and significant development efforts over the last decade, assistive technologies for dementia remain mostly in the realm of research. A major challenge in the commercialization and use of these solutions is low technology adoption rates, despite concerted efforts in this area [10]. Recent evidence suggests technology adoption is closely linked to ethical considerations. The intersection of adoption and ethics can occur at a high level, for example,

when low adoption is due to a misalignment between the needs or values of end users and the benefits of technology solutions [11]. In other cases, specific ethics-related concerns such as conflict of interest or privacy issues impede widespread adoption.

Although ethical issues in technology for people with dementia have been extensively reviewed [12], it can be difficult for technology developers and researchers to implement ethics principles without specific practical guidance within the context of technology-based solutions for dementia [13]. To close the gap between adoption research, ethics, and practice, here we introduce the concept of "ethical adoption," which we define as the deep integration of ethical principles into the design, development, deployment, ongoing usage, and management of technology. Ethical adoption is aimed specifically at technology for dementia and as such is grounded in the theoretical foundation of the principles of biomedical ethics, the standard theoretical framework used to analyze issues at the intersection of ethics and medicine. In this article, we first explore the barriers and facilitators of technology adoption, then describe five pillars of ethical adoption and propose a set of 18 stepwise, practical, and evidence-based recommendations for the development of technology solutions for dementia research and care.

1.1. Determinants of technology adoption

When examining adoption and acceptance of assistive technologies, researchers often profile users based on their engagement or lack thereof with the technology [14,15]. This results in a matrix of adoption, describing whether the person will use the technology based on two factors: whether the technology is usable by the participant and whether they see a perceived utility in the solution.

It is becoming increasingly evident, however, that the likelihood of adoption is much more complex and multifaceted in nature than is described by this two-factor model. Perceptions of usability and usefulness may change over time as individuals change. More importantly, however, the likelihood of adoption spans factors that go beyond the physical design of the solution and individual characteristics of the person with dementia and their carer and also includes social settings and the channels through which the technology is delivered [16].

Several groups have examined factors that act as facilitators or determinants of technology adoption. In a 2014 systematic literature review, Peek et al. [17] found that technology acceptance, which is closely related to adoption, is influenced by 27 factors across six themes: concerns, expected benefits, need, availability of alternatives, social influence, and priorities. Using survey methodology, Lee and Coughlin [18] identified 10 key factors that influence technology adoption (Table 1), with some overlap with Peek et al.'s list.

Table 1
Factors that are considered as facilitators or determinants of technology adoption [18]

Factor	Description
Usefulness	Perception of usefulness and potential benefit
Usability	Perception of user friendliness and ease of learning
Affordability	Perception of potential cost savings
Accessibility	Knowledge of existence and availability in the market
Technical support	Availability and quality of professional assistance throughout use
Social support	Support from family, peers, and community
Emotion	Perception of emotional and psychological benefits
Independence	Perception of social visibility or how a technology makes them look to others
Experience	Relevance with their prior experiences and interactions
Confidence	Empowerment without anxiety or intimidation

In support of these factors, Cook et al. [10] examined the barriers and facilitators to adopting and continuing to use telehealth and telecare solutions by older adults. When analyzing the decision to use assistive technologies, the authors identified four themes: "acceptance of old age/health condition," "previous knowledge and awareness of the equipment available," "perceived usefulness of equipment," and "attitudes and perceptions toward assistive technology." When considering the continued engagement and usage of assistive technologies, four additional and related themes were identified; "usability," "usefulness of equipment," "functionality of equipment," and "threat to identity and independence." The authors highlighted the need for better communication with technology end users and availability of detailed information about the equipment. In addition, "hands-on" demonstrations with a discussion of patient expectations on the support they will need through using the service were deemed critical to support and encourage both adoption and sustained usage.

1.2. Ethical considerations

Technology adoption work has yielded key insights into the factors that promote and deter the adoption, widespread deployment, and sustained use of technology by older adults with and without dementia and their carers. Missing from this endeavor, however, has been the inclusion of ethics as a critical focus point in technology adoption. Technology adoption and technology ethics share many common elements, such as the consideration of risk versus benefit, the possibility of harm (e.g., privacy breach), and social pressure. As such, practical ethical considerations aimed at promoting adoption must inform the delicate balance between the interests of technology users and technology providers. A useful theoretical framework to apply in this context is the four principles of biomedical ethics, namely autonomy, beneficence, nonmaleficence, and justice [19]. Briefly, autonomy refers to the concept of making reasoned, informed decisions for ourselves. Beneficence considers the balance of benefits and risks of a given intervention and the