Commentary

Technology in Dementia Education: An Ethical Imperative in a Digitized World

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Abstract. Technology can support the delivery of care and improve the lives of people living with dementia. However, despite a substantial body of evidence demonstrating the benefits and opportunities afforded by technology, gaps remain in how technology and technology ethics are addressed in dementia care education. Here we discuss disparities in current educational programming and highlight the ethical challenges arising from underdeveloped knowledge exchange about dementia care technology. We put forward that for technology to be ethically deployed and maximized to improve outcomes, it must be embedded into dementia education programs and made widely accessible to the caregiver community.

Keywords: Alzheimer's disease, delivery of health care, ethics, health education, technology

Technology has the potential to transform dementia care. From mainstream digital devices to dementia-specific systems, the continuum of technology offers multiple avenues for caregivers to develop skills and be supported in their roles. Examples of dementia-specific technologies range from simple devices such as reminiscence apps, medication dispensers with reminder functionality or global positioning system-enabled tracking shoe inserts to address challenges related to wandering, to more complex systems such as social robots that are designed to engage, distract, soothe, and assist with activities of daily living [1-7]. However, realizing the benefits afforded by these tools requires a community of technically savvy caregivers and a supportive infrastructure.

Mainstream technologies such as tablets or online learning platforms can be used to effectively deliver dementia education to caregivers. Technology-enabled education harnesses interactive multimedia to provide flexible learning opportunities that can support caregivers in determining what, when and where learning takes place. It complements busy caregiving schedules and has the potential to empower large communities of caregivers across various contexts [8, 9]. Virtual formats have become increasingly accessible, scalable, and cost-effective [10], and advancements in software like augmented and virtual reality now offer new ways of enhancing learning experiences [8, 9, 11]. However, despite these opportunities, the use of technology in dementia education programs is not widespread [12]. This is pertinent given that technology-enabled approaches may be used to significantly improve knowledge about dementia care technologies [13].

Caregivers have mixed opinions about using dementia technologies. Many are curious and welcome opportunities to learn about how technology

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might support caregiving roles [14]. A recent study reported that 54% of caregivers would be less concerned about the safety of a person living with dementia if they were equipped with technology that supports independent living [15]. However, others are concerned that devices will demand advanced technical skills to operate [16] and therefore perceive technology as being outside of their scope of practice [14]. Caregivers have also expressed fears about technology having a negative impact, including the potential for decreased caregiver vigilance as a result of over-reliance on technical functions [17]. For caregivers aged over 65, who account for 19% of the older adult population in the United States [18], the barriers to using dementia technologies may be exacerbated by low digital literacy, perceptions of mistrust, and digital exclusion. Concerns around privacy, confidentiality, and autonomy represent additional challenges to adoption [4, 19–22] with both persons living with dementia and caregivers expressing concerns about the risk of unwanted disclosure of private or personally identifying information [23-26]. Taken together these challenges highlight the importance of strengthening the digital competencies of caregivers and equipping them to harness the benefits of available solutions in a way that aligns with their values.

The WHO's Global Action Plan on the Public Response to Dementia called for international action to improve access to technological innovations that facilitate support for caregivers and enhance caregiver knowledge and skills [27]. This has since been operationalized across North America. The Dementia Strategy for Canada: Together We Aspire, called for caregivers to be better equipped to deliver quality care with evidence-based tools and resources [28]. In the United States, the National Research Summit on Dementia Care, and the National Alzheimer's Project Acts' Advisory Council on Alzheimer's Research, Care, and Services have identified dementia education and training in technology as priority areas of focus [29, 30]. The Alzheimer's Association's Professional Interest Area for Technology in Dementia and AGE-WELL NCE's EPIC-AT programs are noteworthy initiatives that have since been implemented in their respective countries to address these priority areas [31, 32]. However, while educational programs such as these (and others [33, 34]) are helping to tip the balance in favor of optimizing dementia care technology, they are mostly limited to professional audiences. Training offered to lay caregivers is less developed.

To survey public-facing dementia care training programs which might be easily accessed by lay caregivers, we performed a Google search using the keywords dementia, online, training, health care provider, and their synonyms. The first five pages of results returned 207 training programs, delivered by 89 providers. Large variation was found in the quality and depth of educational content, and among program characteristics such as delivery format, cost, duration, and accreditation. Content analysis of course descriptions revealed that few (15%) program providers offered comprehensive training curricula (scoring ≥ 15 when coded against 20 themes related to dementia caregiving including care approaches, communication, and wellbeing). Only 2% of providers explicitly mentioned technology in their program descriptions. Programs rarely attributed content to evidence-based sources, which called into question the credibility of the training material. Such oversight leaves room for the spread of disinformation or the use of predatory marketing tactics [35, 36]. These complexities make it challenging to identify and access quality dementia education. Publicly available training on dementia care technologies is particularly scarce.

We have reached a critical point. Technologies are continuing to advance and demonstrate increasing application to dementia care. However, training programs that equip caregivers with the skills to utilize these technologies lag behind.

We must address the gaps in caregiver education and tackle unequal distribution of resources. It is widely known that training caregivers leads to better outcomes [37-40]. For caregivers, dementia training improves overall wellbeing and role satisfaction [39], and significantly improves knowledge, attitude, and confidence [37]. For care recipients, training leads to positive outcomes in quality of life, communication, behavioral and psychological symptoms, and activities of daily living [41]. It follows, that empowering caregivers with the skills to optimize dementia technologies may support autonomy, self-determination, and beneficence for both parties. Failure to provide caregivers with opportunities to strengthen digital competencies about dementia care technology, therefore risks disempowering the very people they are intended to benefit. Just distribution of resources is necessary to safeguard the rights of people living with dementia [42, 43].

Information about technology must be transparent and openly weigh promises against user concerns to foster trust and dismantle barriers to adoption [4,

44]. Frequently cited concerns include those related to data collection and the potential harms of digital surveillance through excessive monitoring and privacy intrusions. Storage and disclosure of personally identifying or health information are associated concerns, especially with regard to the possibility of unauthorized use of data by third-party companies or the sharing of sensitive information that leads to discrimination and stigma [21, 23, 24, 26, 45]. Therefore, responsible deployment of technology necessitates that education and training must be delivered to address such concerns and raise awareness of the checks and balances that may be employed to safeguard user rights, thus empowering people with the knowledge and skills to make informed decisions. Rapid advancements in the functionalities of dementia technologies and the increasing prominence of software such as artificial intelligence in healthcare contexts, add further emphasis to the urgency and centrality of education in the ethical adoption of technology [44]. The promises of technology cannot translate into benefits if awareness remains low [46, 47].

Dementia care technologies are at the intersection of technology and medical ethics; ethical, legal and social issues around the implications of technology use overlap with the merits and challenges of care practices. Safeguarding human rights and upholding these shared principles is therefore a mandate that must lead developments in educational programming about dementia technology. The current landscape of training is complex, with pockets of excellence and room for improvement. With rising pressure to increase care capacity, timely action is needed to improve the disparities in caregiver education so that technology may be ethically deployed and optimized by people living with dementia to live well and flourish.

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CONFLICT OF INTEREST

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REFERENCES

- [1] Dosso JA, Bandari E, Malhotra A, Hoey J, Michaud F, Prescott TJ, Robillard JM (2022) Towards emotionally aligned social robots for dementia: Perspectives of care partners and persons with dementia. Alzheimers Dement 18, e059261.
- [2] Ienca M, Wangmo T, Jotterand F, Kressig RW, Elger B (2018) Ethical design of intelligent assistive technologies for dementia: A descriptive review. Sci Eng Ethics 24, 1035-1055
- [3] Ryan AA, McCauley CO, Laird EA, Gibson A, Mulvenna MD, Bond R, Bunting B, Curran K, Ferry F (2020) 'There is still so much inside': The impact of personalized reminiscence, facilitated by a tablet device, on people living with mild to moderate dementia and their family carers. *Dementia* 19, 1131-1150.
- [4] Robillard JM, Wu JM, Feng TL, Tam MT (2019) Prioritizing benefits: A content analysis of the ethics in dementia technology policies. *J Alzheimers Dis* 69, 897-904.
- [5] Wójcik D, Szczechowiak K, Konopka P, Owczarek M, Kuzia A, Rydlewska-Liszkowska I, Pikala M (2021) Informal dementia caregivers: Current technology use and acceptance of technology in care. *Int J Environ Res Public Health* 18, 3167.
- [6] Knapp M, Barlow J, Comas-Herrera A, Damant J, Freddolino P, Hamblin K, Hu B, Lorenz K, Perkins M, Rehill A, Wittenberg R, Woolham J (2015) The case for investment in technology to manage the global costs of dementia, Policy Innovation Research Unit, London, United Kingdom.
- [7] Marston HR, Musselwhite CBA (2021) Improving older people's lives through digital technology and practices. *Gerontol Geriatr Med* 7, 233372142110362.
- [8] Alzheimer's Disease International (2022) World Alzheimer Report 2022. Life after diagnosis: Navigating treatment, care and support. Alzheimer's Disease International, London, England.
- [9] Muirhead K, Macaden L, Smyth K, Colin Chandler, Clarke CL, Polson R, O'Malley C (2022) The characteristics of effective technology-enabled dementia education: A systematic review and mixed research synthesis. Syst Rev 11, 34
- [10] Noel MA, Lackey E, Labi V, Bouldin ED (2022) Efficacy of a virtual education program for family caregivers of persons living with dementia. *J Alzheimers Dis* 86, 1667-1678.
- [11] Jones C, Jones D, Moro C (2021) Use of virtual and augmented reality-based interventions in health education to improve dementia knowledge and attitudes: An integrative review. *BMJ Open* **11**, e053616.
- [12] Newbould L, Samsi K, Wilberforce M (2022) Developing effective workforce training to support the long-term

- care of older adults: A review of reviews. *Health Soc Care Community* **30**, 2202-2217.
- [13] Berridge C, Turner NR, Liu L, Fredriksen-Goldsen KI, Lyons KS, Demiris G, Kaye J, Lober WB (2023) Preliminary efficacy of let's talk tech: Technology use planning for dementia care dyads. *Innov Aging* 7, igad018.
- [14] Kristiansen S, Beck M, Kabir ZN, Konradsen H (2022) Providing dementia care using technological solutions: An exploration of caregivers' and dementia coordinators' experiences. *J Clin Nurs* 31, 1874-1883.
- [15] Longitude Prize on Dementia offers new hope in helping people with dementia stay independent, https://www.alzheimers.org.uk/news/2022-09-26/long itude-prize-on-dementia-helping-people-dementia-stayindependent, Last updated 2022, Accessed on December 14, 2022.
- [16] Hicks B, Karim A, Jones E, Burgin M, Cutler C, Tang W, Thomas S, Nyman SR (2022) Care home practitioners' perceptions of the barriers and facilitators for using offthe-shelf gaming technology with people with dementia. *Dementia* 21, 1532-1555.
- [17] Felber NA, Tian YJ (Angelina), Pageau F, Elger BS, Wangmo T (2023) Mapping ethical issues in the use of smart home health technologies to care for older persons: A systematic review. BMC Med Ethics 24, 24.
- [18] Caregiving for Family and Friends A Public Health Issue, https://www.cdc.gov/aging/caregiving/caregiverbrief.html, Last updated July 31, 2019, Accessed on May 10, 2023.
- [19] Kabacińska K, Vu K, Tam M, Edwards O, Miller WC, Robillard JM (2023) "Functioning better is doing better": Older adults' priorities for the evaluation of assistive technology. Assist Technol 35, 367-373.
- [20] Astell AJ, Bouranis N, Hoey J, Lindauer A, Mihailidis A, Nugent C, Robillard JM, Technology and Dementia Professional Interest Area (2019) Technology and dementia: The future is now. *Dement Geriatr Cogn Disord* 47, 131-139.
- [21] Abu Seman AH, Ahmad R, Alhassan Alhussian HS (2020) Factors influencing acceptance of technology by senior citizens: A systematic review. In *Intelligent Algorithms in Software Engineering*, Silhavy R, ed. Springer International Publishing, Cham, pp. 352-365.
- [22] Howard J, Fisher Z, Kemp AH, Lindsay S, Tasker LH, Tree JJ (2022) Exploring the barriers to using assistive technology for individuals with chronic conditions: A meta-synthesis review. *Disabil Rehabil Assist Technol* 17, 390-408
- [23] Dosso JA, Kailley JN, Guerra GK, Robillard JM (2023) Older adult perspectives on emotion and stigma in social robots. Frontiers in Psychiatry 13, 1051750.
- [24] Berridge C, Zhou Y, Robillard, Kaye J (2023) AI companion robot data sharing: Comfort and preferences of an online cohort with policy implications. *J Elder Policy* **2**, 19-54.
- [25] Robillard JM, Lai J-A, Wu JM, Feng TL, Hayden S (2018) Patient perspectives of the experience of a computerized cognitive assessment in a clinical setting. *Alzheimers Dement* 4, 297-303.
- [26] Robillard JM, Goldman IP, Prescott TJ, Michaud F (2020) Addressing the ethics of telepresence applications through end-user engagement. J Alzheimers Dis 76, 457-460.
- [27] World Health Organization (2017) Global action plan on the public health response to dementia 2017–2025, World Health Organization, Geneva, Switzerland.

- [28] Public Health Agency of Canada (2019) A Dementia Strategy for Canada: Together We Aspire.
- [29] Weiss J, Tumosa N, Perweiler E, Forciea MA, Miles T, Blackwell E, Tebb S, Bailey D, Trudeau SA, Worstell M (2020) Critical workforce gaps in dementia education and training. J Am Geriatr Soc 68, 625-629.
- [30] National Alzheimer's Project Act (2022) Public members of the Advisory Council On Alzheimer's Research, Care And Services: 2022 Recommendations.
- [31] ISTAART. PIA. Technology and Dementia, https://ac tion.alz.org/PersonifyEbusiness/Default.aspx?TabID=1621, Last updated 2023, Accessed on January 23, 2023.
- [32] Early Professionals, Inspired Careers in AgeTech (EPIC-AT) Health Research Training Program, AgeTech EPIC-AT, https://agewell-epic.ca/, Last updated 2022, Accessed on January 4, 2023.
- [33] SDRC, Special Interest Group for Brain Health and Dementia Prevention, https://www.sdrc.scot/technologies-sig, Last updated 2023, Accessed on May 25, 2023.
- [34] Centre for Dementia Learning | Dementia Australia, https://dementialearning.org.au/, Last updated January 30, 2020, Accessed on May 25, 2023.
- [35] Robillard JM (2016) The online environment: A key variable in the ethical response to complementary and alternative medicine for Alzheimer's disease. *J Alzheimers Dis* 51, 11-13.
- [36] Hrincu V, An Z, Joseph K, Jiang YF, Robillard JM (2022) Dementia research on Facebook and Twitter: Current practice and challenges. J Alzheimers Dis 90, 447-459
- [37] Scerri A, Scerri C (2019) Outcomes in knowledge, attitudes and confidence of nursing staff working in nursing and residential care homes following a dementia training program. Aging Ment Health 23, 919-928.
- [38] Spector A, Orrell M, Goyder J (2013) A systematic review of staff training interventions to reduce the behavioral and psychological symptoms of dementia. Ageing Res Rev 12, 354-364
- [39] Spector A, Revolta C, Orrell M (2016) The impact of staff training on staff outcomes in dementia care: A systematic review. Int J Geriatr Psychiatry 31, 1172-1187.
- [40] Vandepitte S, Van Den Noortgate N, Putman K, Verhaeghe S, Faes K, Annemans L (2016) Effectiveness of supporting informal caregivers of people with dementia: A systematic review of randomized and non-randomized controlled trials. J Alzheimers Dis 52, 929-965.
- [41] Surr CA, Parveen S, Smith SJ, Drury M, Sass C, Burden S, Oyebode J (2020) The barriers and facilitators to implementing dementia education and training in health and social care services: A mixed-methods study. BMC Health Serv Res 20, 512.
- [42] World Dementia Council (2021) Global dialogue on technology: Reflections. The dementia landscape project. Essays from international leaders in dementia., World Dementia Council, London, United Kingdom.
- [43] Canadian Charter of Rights for People with Dementia, https://alzheimer.ca/en/take-action/change-minds/canadian-charter-rights-people-dementia, Accessed on December 19, 2022.
- [44] Robillard JM, Cleland I, Hoey J, Nugent C (2018) Ethical adoption: A new imperative in the development of technology for dementia. Alzheimers Dement 14, 1104-1113.
- [45] Robillard JM, Kabacińska K (2020) Realizing the potential of robotics for aged care through co-creation. *J Alzheimers Dis* 76, 461-466.

- [46] Wang RH, Wilson MG (2022) It is time for a national strategy on equitable access to assistive technology in Canada. Healthc Manage Forum 35, 356-362.
 [47] Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M,
- [47] Lorenz K, Freddolino PP, Comas-Herrera A, Knapp M, Damant J (2019) Technology-based tools and services for

people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia* 18, 725-741.