

Privacy, Consent, and Care: Rethinking the Ethics of Dementia Technologies

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Abstract- Dementia is a growing concern among ageing populations, necessitating an urgent need for safe, autonomous, and equitable ageing-in-place conditions. Digital technology, such as AI monitoring, sensors, and social robots, enhances safety and independence. However, important questions concerning privacy, dignity, consent, and access need to be addressed. Against this backdrop, this study provides evidence from ethics, technical, and governance discourses to evaluate whether dementia care technologies can be responsibly designed and implemented. Findings indicate that innovation outpaces ethics and regulation, resulting in contradictions between safety and autonomy, surveillance and dignity, and innovation and equity. Therefore, this study proposes participatory co-design, adaptive consent models, privacy-by-design principles, and foresight governance as necessary measures to ensure that technology augments, but never replaces, human care. Putting ethics and consumers' voices at the centre of innovation is essential to protect human rights and the dignity of dementia patients and their carers.

Keywords: Dementia Care, Ethical UX Design, Autonomy and Consent, Digital Tracking, Personalization

I. INTRODUCTION

Millions of individuals worldwide have dementia and are projected to rise from 46.8 million in 2015 to 131.5 million by 2050^{1, 2}. The foremost goal in dementia care is "ageing in place", which enables people with dementia (PWD) to remain safely at home within a conducive environment and social networks³. Dementia limits the victims' cognitive ability to make complex choices⁴, with behavioural symptoms such as wandering posing significant safety risks often lead to institutionalisation⁵. While regular non-drug management (such as exercise or music therapy) offers a limited remedy⁶, in contrast, environment adaptation or physical restraint poses ethical concerns as to protection and self-determination⁷.

To address this, assistive technologies (DATs) like electronic tracking equipment, home automation, and artificial intelligence-tracked monitoring aim to promote security, autonomy, and caregiver support^{8, 9}. Nonetheless, these innovations have outpaced the development of ethical, legal, and governance principles, and concerns about privacy, dignity, and justice remain unresolved^{10, 11}. The extant literature reveals that technical performance outstrips lived experience, and ethical principles are recognised but rarely applied¹². Additionally, dementia patients and carers remain under-represented in design and policymaking; thus, they are often served by a range of solutions that are not in best fit for their healthcare needs¹³.

Against this backdrop, this study seeks to address these challenges by synthesising ethical theory, empirical findings, and governance strategies to make recommendations for participatory co-design, adaptive consent, and privacy-aware frameworks as pathways towards responsible innovation in dementia technologies. The remainder of the paper is organised as follows: Section 2 examines ethical design and implementation; Section 3 discusses privacy, surveillance, and tracking ethics; Section 4 explores emerging technologies and consequences; Section 5 covers policy and governance; and Section 6 concludes with key recommendations.

II. ETHICAL DESIGN & IMPLEMENTATION OF DEMENTIA TECHNOLOGIES

Ethical design goes beyond technical efficiency towards user-centred, inclusive, and ability-sensitive systems that complement human care instead of replacing it.¹⁴ Studies show that adoption is hindered by technical factors such as low interoperability; economic and political constraints, including high cost and unclear regulation; and user-level barriers like stigma and low digital literacy.^{14, 15} Successful innovations require early adoption, embedding within

communities, and integration into dementia-responsive health systems.

The most prominent ethical challenges are privacy, autonomy, design manipulation (e.g., nudging), and informed consent amid declining cognition.¹⁶ Ageing populations value control and agency, such as the ability to suspend monitoring or switch off video recording, suggesting that assuming passive use may discourage engagement.¹⁷ Ethical innovation is therefore aligned with the ethical principles of autonomy, dignity, beneficence, non-maleficence, justice, and privacy; facilitated by adaptive consent, bias mitigation, and continuous human oversight.^{18, 19} Robillard et al.²⁰ delineate five pillars of ethical adoption, as illustrated in Figure 1.

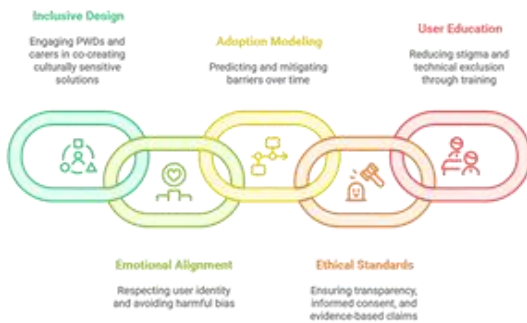


Fig. 1: Five Pillars of Ethical Adoption

Source: Author’s visual adapted from Robillard et al.²⁰

The principles demand engagement, empathy, and openness as conditions for trust. In addition, adoption further depends on addressing loneliness, ensuring technology is used to augment rather than replace care, and protecting data through opt-in sharing, encryption, privacy-preserving sensors, and bounded third-party access.²¹ Therefore, ethical dementia technology requires participatory, value-pluralistic, and privacy-respecting design through anticipatory governance. Such a design embeds user values in practice, maintains dignity and safety, and enables truly responsible innovation.

III. PRIVACY, SURVEILLANCE, AND TRACKING ETHICS

Electronic tagging technologies (ETTs), such as GPS and RFID systems, enhance the autonomy and safety of people with dementia (PWDs) by lowering caregiver burden and delaying institutionalization.^{7,10, 22} However, they pose significant ethical issues regarding autonomy, dignity, and surveillance. Although referred to as autonomy-enhancing devices, ETTs can infantilise users, erode identity, and commodify care into behaviour control under constant surveillance.^{7, 10, 23} Privacy concerns involve ownership of information, safety, and informed consent, particularly as decision-making capacity fluctuates.⁷ Dementia undermines informed consent; therefore, advance directives and pre-stage consultation regarding the application of technology are justified.^{24, 25}

Furthermore, issues of justice include stigma, disparate access, and the substitution of surveillance technologies for relational care.²⁶ ETTs also have the potential to heighten caregiver burden through round-the-clock monitoring requirements and create a false sense of security without necessarily preventing accidents or exploitation.⁷ Community-based programs like the American *Silver Alert* and its equivalents in Canada facilitate the recovery of missing persons but are subject to risks of privacy invasion, stigmatisation, and data misuse.^{7, 27, 28} Legislation for privacy, such as Canada’s *Privacy Act* and *PIPEDA*, exists to protect privacy but may also constrain innovation.²⁹

Ethical guidance recommends minimal disclosure, advance care planning, and early formal decision-making to balance safety with autonomy.^{25, 30, 31} Evidence shows that GPS and alert systems are most effective when introduced early in the disease, involving PWDs, carers, and practitioners in defining the boundaries and parameters of consent.³⁰ However, public disclosure of personal information, such as photographs or cognitive function, can erode dignity and reinforce stigma.³¹

IV. EMERGING TECHNOLOGIES AND THEIR ETHICAL IMPLICATIONS

Digital assistive technologies (DATs), from home monitoring systems and mobile health applications to AI-assisted systems, are transforming dementia care by enabling independence, reducing caregiver burden, and supporting ageing in place.^{19, 20} Initiatives such as the UK's Technology Integrated Healthcare Management (TIHM) project demonstrate the potential of AI-assisted monitoring to detect deviations in behaviour and prevent hospitalization.³² Fluctuating decision-making capacity complicates informed consent and creates ethical challenges surrounding autonomy, dignity, and safety.³³ AI systems also introduce risks of bias, opacity, and privacy–autonomy trade-offs, which undermine accountability in care delivery.³⁴ Traditional medical ethics (justice, autonomy, non-maleficence, and beneficence) become difficult to apply when cognitive impairment limits an individual's capacity.³⁵

Human–Computer Interaction (HCI) research explores AI-driven personalisation that dynamically adapts to users' changing cognitive and physical abilities.³⁶ Persons with dementia (PWDs) expect AI to assist with prospective and retrospective memory functions but remain doubtful regarding data sharing, privacy, and the perceived “*humanness*” of AI systems. While automation can relieve carers of routine burdens, emotional and empathic human care cannot be replicated by machines. Social and companion robots can stimulate cognitive and emotional engagement, yet raise ethical concerns about consent, autonomy, privacy, and infantilization.^{37, 38} By blurring boundaries between tool and companion, such technologies challenge notions of identity, dignity, and relationality in care. Governments, through frameworks such as the EU AI Act and emerging robotics policies, continue to grapple with cross-cultural heterogeneity and persistent inequities in access and governance.^{39, 40} Scholars caution against techno-optimism and the concept of “*cruel optimism*,” in which technology's promise of freedom conceals dependency or replaces authentic relational care.⁴⁰ Seniors are more inclined to adopt robotic technologies when these are accessible, digitally inclusive, and enhance human

communication rather than replace it. Ethical implementation of emerging technologies thus requires dementia-capable, inclusive co-design that centres dignity, justice, and interdependence, anchored in empathy and human oversight.³⁷

V. POLICY, GOVERNANCE, AND BROADER ETHICAL FRAMEWORKS

Despite the rapid innovation in dementia care technologies, policy and governance remain fragmented and ethically inconsistent. Most frameworks emphasize the theoretical benefits (such as safety, autonomy, and reduced caregiver burden) while overlooking threats to privacy, potential harms, and the nuanced meaning of autonomy.^{12, 17} Although moral principles like beneficence, non-maleficence, justice, and autonomy are frequently invoked, their operational translation into design, deployment, and accountability is rarely realized. Furthermore, dementia patients and their caregivers are seldom involved in policymaking processes, perpetuating a gap between technological innovation and ethical oversight. This gap is particularly pronounced in emerging technologies such as AI and robotics, where regulatory systems lag behind evolving challenges of consent, data stewardship, algorithmic bias, and the erosion of human-centred care.

Empirical evidence highlights these mismatches between policy and practice, with low usability, exclusionary design, and poor integration into existing care systems commonly reported.¹³ While people with dementia express willingness to adopt autonomy-supportive technologies and engage early in their design, they are rarely included in the early stages of development. Only a few products address the heterogeneity of user needs, and evidence on cost-effectiveness remains limited. Barriers to adoption persist due to a lack of awareness, limited technical literacy, design flaws, and unsustainable business models. Ethical dimensions, such as balancing autonomy and safety, protecting privacy, and securing informed consent, are frequently cited yet inconsistently defined and measured. Therefore, researchers and policymakers must adopt anticipatory and participatory governance that embeds ethics at the forefront of innovation, ensuring that regulatory frameworks are responsive to new risks.^{12, 13} Such

frameworks should foster accountability, transparency, justice, and social legitimacy, aligning innovation with public trust and the well-being of end users.

VI. CONCLUSION AND RECOMMENDATIONS

Dementia technology has vast potential to deliver safety, independence, and assistance for carers, but this is undermined by neglected ethics and governance. Issues like surveillance, unequal access, poor consent, and subversion of human-focused care raise ethical concerns, pinpointing the need for participatory ethics-driven innovation. Therefore, this study advocates for the following core priorities to guide responsible innovation in dementia technology:

- i. Integrating ethics in design and delivery through codesigning with carers and people with dementia to preserve autonomy, dignity, and diverse user requirements.
- ii. The use of adaptive consent models anticipates cognitive deterioration and enabling early, structured decision-making.
- iii. Increase control and privacy of information through low-disclosure data handling, encryption, and restrictions on third-party access.
- iv. Establish active policy and regulatory frameworks balancing accountability, equity, and long-term sustainability with innovation.

By making participatory governance and ethical foresight paramount, dementia technologies can facilitate dignity, trust, and at-home ageing in ways that ensure that innovation serves not technology for its own sake, but also human values most central to care.

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