Commentary

Co-Designing Location-Based Services for Individuals Living With Dementia: An Overview of Present and Future Modes of Operation

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Dementia is an encompassing term used to define a series of "neurological conditions, of which the major symptom includes a global decline in brain function" [17]. Alzheimer's Disease International [6] reports that every three seconds, one person worldwide will develop dementia. The not-for-profit also noted that there are 55 million individuals living with dementia and it is projected that by 2050, this number will increase to 139 million. In Australia alone, an estimated 487,500 individuals are living with various forms of dementia, with 70% residing in the community, requiring 1.6 million carers [15]. A recent report during Dementia Action Week stated that despite the increased appreciation of the fundamental rights of individuals living with dementia, many were still subject to discrimination and lacked societal inclusion [16]. This article maintains that dimensions of equity and inclusion are pertinent to discussions around technological solutions developed with the dementia community, specifically, future artificial intelligence-enabled options that may, unless carefully designed, exacerbate or amplify issues of discrimination, marginalization, and personhood.

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Dementia, human rights, and location-based services

The impact of dementia is such that the World Health Organisation has identified it as a "public health priority." This typically results in individuals having their basic rights diminished [40], as individuals living with dementia may find themselves in a vulnerable state, not long after diagnosis. For instance, an individual may be unable to return home or feel disoriented in an unfamiliar context lacking the cognitive ability to retrace their movements. This is often referred to as "wandering," which is a term that is contentious and may be considered unconstructive, as it "suggests that the person is walking without purpose, whereas they will often have a reason for it"; therefore, the term "walking about" can be used instead [7]. Representative reasons for walking about include changes to the environment; the need to use surplus energy; searching for the past, such as for people or places; and following through on dreams given the difficulty in distinguishing between reality and dreaming [18]. There are many additional reasons. As such, a common challenge for the dementia community is concurrently maintaining the safety, freedom, and well-being of individuals living with dementia in these circumstances [3].

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Studies in location-based services (LBSs) and associated emerging technologies often investigate the use of technological devices and solutions that could benefit the dementia community in these situations, given the lifesaving potential facilitated by location monitoring and tracking capabilities [26], [31]. Select literature in the LBS domain points to the associated ethical implications such as privacy and issues of consent [3], [10], [13], [22], [23], [25], [39], in addition to regulatory considerations [1], [4], [5], [12], [41]. In this article, the emphasis is on these implications, from the position of two modes of operation—the present and future modes—as applied to the dementia community.

Present mode of operation: Standalone and off-the-shelf solutions

In the present mode of operation, there are commercial LBSs that allow for the tracking and monitoring of wearable and luggable devices that can be adopted by the dementia community [19]. Typically, these devices are marketed and sold as standalone units, to be purchased and utilized in a voluntary capacity by inexperienced carers and other end-users, with the purpose of maintaining the safety of a loved one (see [8] and [29]). A reported concern is that off-the-shelf solutions are not necessarily sensitive to the specific needs of people living with dementia [14] nor their caregivers and caretakers. That is, while current LBS solutions may be perceived by some as easy to use and intuitive when implemented across common use cases (e.g., in-vehicle navigation and emergency management), this article maintains that most solutions are generally designed and developed for the mass market, with a focus on optimal technological performance rather than the *lived experience* of individuals living with dementia. As such, the balancing of technological requirements and performance with the lived experience of individuals is advocated for in this article. Another key challenge with commercial LBS applications intended for the dementia community is that caregivers are often required to assume responsibility for the selection of location services and complementary units. Yet, those tasked with the responsibility to purchase appropriate technology cannot be assumed to possess adequate technical skills to navigate the selection environment and may not necessarily be aware of the associated ethical and other challenges identified above.

Future mode of operation: Intelligent, embedded, and AI-enabled location services

A future mode of operation pertaining to LBS solutions for individuals living with dementia is emerging, further complicating decisions pertaining to the design, development, selection, and implementation of LBS solutions for individuals living with dementia. There are two fundamental ways that location services can be implemented, either device-based in the case of a handset that contains a GPS chipset onboard, or network-based solutions that rely on triangulation to determine location. These are for the greater part consumer opt-in solutions relevant to the present mode of operation. However, future modes will likely involve automated detection of dementia or other health conditions, implemented at the level of the city rather than the individual. Already smart city solutions are being trialed, whereby intelligent or AI-enabled LBS solutions would utilize machine learning algorithms with corresponding training data sets to preemptively ensure a range of outcomes, such as the safety and security of individuals living with dementia [21]. Such preemptive options could involve early diagnosis or detection of cognitive decline by studying the gait or movement patterns of those individuals living with dementia, after which AI could be utilized to detect cues or early warning signs of disorientation using biometric-enabled CCTV that is deployed on urban infrastructure, for example, lampposts [20], [27], [37], [38]. The individuals considered "at-risk" in diverse use case scenarios would then automatically trigger an appropriate response if they were preregistered on either privately owned or publicly administered platforms. Specifically, the use of, and ability to integrate, biometric data such as an individual's location chronicle, facial characteristics, and gait results in the transition from traditional personalization-based location applications that depend on a token carried by the individual living with dementia, to those that additionally offer increased accuracy of information and service provisioning; enhanced recommendations; and predictive analytics capabilities embedded in the environment [9], [11]. This would theoretically provide the ability to introduce personalized care, implement appropriate intervention strategies, and ensure the prolonged independence of individuals living with dementia and their caregivers. But at what cost?

Challenge: Transitioning from a technology-centric perspective

While there are clear opportunities within the context of present and future modes of operation, technology, and specifically AI-driven location solutions alone are insufficient to facilitate the safety and freedom of individuals living with dementia. Furthermore, as we consider future modes of operation, intelligent, embedded, and AI-driven LBS solutions may exacerbate the marginalization of individuals living with dementia or those exhibiting patterns of behavior aligned with this neurocognitive condition. Identifying at-risk individuals can be desirable from the perspective of preventive and proactive approaches to care and safety, but also provides opportunities for exploitation, such as surveillance, prohibiting access to certain services, and compromising the autonomy and dignity of individuals. Emerging from these scenarios is an evident power asymmetry between individuals living with dementia/their caregivers or caretakers and the entities or stakeholders who will be in command of the LBS systems or platforms, notably those who are responsible for the collection, storage, dissemination, and use of location and other contextual information (in present modes) to individuals designing the machine learning algorithms and smart cities (in future modes). Socio–technical challenges concerning privacy, ethics, security, data ownership, control, and more must be considered in both present and future modes of operation.

Way forward: Socio–technical co-design

In terms of a proposed path forward using a socio–technical systems approach, this article contends that irrespective of the technical implementation option chosen, the emphasis of any proposed solution or platform must be on care through participatory design methods, such as compassionate design [33], [35], as well as approaches that promote stakeholder wellbeing [34], as opposed to a technology-centric perspective. A promising and suggested approach here is the socio–technical co-design of a dedicated care platform, oriented toward facilitating the safety and freedom of people living with dementia using LBS and other complementary technologies through convergence. The proposed platform would be co-designed by not only the individual living with dementia, but other stakeholders such as caregivers/caretakers/family members, health and medical professionals, law enforcement agencies, technology providers, government agencies, academic institutions, peak bodies, and more. This human-centered approach will support and allow for the integration of the requirements of individuals living with dementia and the identified ethical/other challenges, in the underlying design of the proposed system, while also supporting the needs of other stakeholders in the dementia community. Fundamental to the process is the employment of existing and suitable participatory approaches for engaging individuals living with dementia [28], [32], [42], noting that "collaborative mixes of co-design and cocreation" may be required [36, p. 927].

Furthermore, the selected co-design methodologies must be empathetic in their underlying design and aid in desirably influencing and restoring the self-esteem, dignity, identity, and feelings of community connectedness of an individual living with dementia [30]. The application of the socio–technical co-design approach in dementia and health context signals an important change from the dominant technological focus in the LBS industry to the balancing of the social dimension, which emphasizes care, compassion, and other values such as central to socio–technical systems design. The ideal scenario is the simultaneous provision of safety and freedom, through community empowerment in the socio–technical design process, granting a voice to community members during the design phase and potentially the development of current and future socio–technical solutions, location-based or otherwise. The success of the proposed socio–technical co-design approach is largely reliant on our willingness to actively listen to capture lived experience and reconcile this experience with professional expertise in a practical design setting, to enable us to proactively address a range of ethical challenges, including privacy, consent, and issues of discrimination, marginalization, and personhood. ■

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