COS 70004 – User Centred Design

Individual research report

Modern Solutions for Preventing Dementia-Related Wandering and Reducing Caregiver Burden

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Acknowledgement to Country

I am grateful for the opportunity to attend Swinburne University of Technology and study on the ancestral lands of the Kulin Nation, which is now home to Melbourne. My sincere appreciation goes out to the Wurundjeri People, who have historically been the guardians of this country. My gratitude also goes out to the Swinburne community's Aboriginal and Torres Strait Islander students, graduates, partners, and guests. Recognising the rich cultural, historical, and spiritual legacy of the Wurundjeri country is an honour, and I take great satisfaction in honouring it.

Executive Summary

This report explores the role of GPS technology in managing dementia-related wandering while reducing caregiver stress. Drawing from studies by **Doyle et al., (2024)** and **Qiang et al., (2018)** as well as real life implementations from established companies, it evaluates the feasibility and effectiveness of GPS trackers. These devices have been shown to significantly improve the safety and independence of **people with dementia (PwD)** by enabling real-time monitoring and customisable geofencing. Additionally, they reduce emergency interventions and delay the need for full-time care **(Doyle et al., 2024).**

Despite the promise, challenges such as device usability and privacy concerns persist. Cognitive impairments in PwD and network signal issues may limit effectiveness in some cases. However, future improvements, such as machine learning for personalized geofencing and dynamic consent systems to protect privacy, can enhance usability and effectiveness. **(Doyle et al., 2024).**

Key recommendations include integrating data mining techniques and machine learning for adaptive geofencing, improving communication features for caregivers, an easy to use and customisable user interface and incorporation of privacy controls. These improvements will ensure the wandering detection app is more user-friendly and secure, offering better support for PwD and caregivers. **(Doyle et al., 2024).**

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1.Introduction

Wandering is a dangerous behaviour in **people with dementia (PwD)**, often leading to confusion, injury, or even death. Surveys show that over **60%** of PwD are likely to wander, putting pressure on caregivers to ensure safety while respecting freedom. With the global dementia population projected to increase from the current count of **55 million** to **139 million by 2050**, it's crucial to find better ways to manage this issue **(Alzheimer's Disease International, 2022).**

The main project aims to create an accurate and efficient user interface prototype of a wandering detection app to help caregivers by using GPS technology. Caregivers can track PwD in real time, receive alerts when they leave safe areas, and set virtual boundaries. This report focuses on an in-depth review of key research findings by **Doyle et al. (2024)** which evaluate the effectiveness of GPS tracking systems in reducing wandering incidents and providing peace of mind to caregivers. The goal is to design a more practical and user-friendly app that addresses ethical concerns and improves the caregiving process. **(Doyle et al., 2024).**

2. In-depth Analysis of the Research paper

2.1 Methodology of the Doyle Research paper

Doyle et al., (2024) carried out a six-month study, combining interviews and data analysis to assess how practical and user-friendly GPS trackers are, for people with dementia (PwD) and their caregivers **(Doyle et al., 2024).**

Study Design:

- Initially, **71** individuals were referred for participation. Out of these, **45 dyads (PwD and their caregivers together constitute 1 dyad)** were selected to take part in the study **(Doyle et al., 2024).**

Data Collection:

- Assessments were conducted at the beginning (baseline) and after six months **(Doyle et al., 2024).**
- Monthly check-ins, either through phone calls or in-person visits, were used to monitor GPS usage and collect feedback **(Doyle et al., 2024).**
- In-depth insights were gathered from four focus groups, which included 14 dyads and 3 external stakeholders **(Doyle et al., 2024).**

Inclusion/Exclusion Criteria:

- Participants needed a confirmed dementia diagnosis and had to be at risk of wandering. They also needed to reside in the Barnsley or Wakefield districts, with a designated caregiver to monitor them **(Doyle et al., 2024).**
- PwD in full-time care facilities were excluded from the study **(Doyle et al., 2024).**

Intervention:

- Participants were provided with GPS trackers, which could be worn on a lanyard, keyring, or carried in a bag **(Doyle et al., 2024).**
- Caregivers were trained on the GPS features, including real-time tracking, geofencing (which alerts when PwD leave safe zones), two-way communication, and fall detection alerts **(Doyle et al., 2024).**

Outcome Measures:

- **Primary outcomes:** The study assessed the feasibility and acceptability of the GPS trackers, with an **85%** completion rate and no major incidents reported **(Doyle et al., 2024).**
- **Secondary outcomes:** Caregivers reported a **5**-point reduction in their burden, and safe wandering behaviours increased by **6** points. Quality of life and ease of use were also evaluated, indicating positive results **(Doyle et al., 2024).**

2.2 Key Learnings and results from the Doyle Research Paper

Certain key findings were observed, based on the results of the above study carried out by **Doyle et al., (2024)**. The study had a **76%** completion rate, with **34 dyads** completing the trial, while **24% of** participants dropped out due to factors such as the deterioration of PwD's health or their admission to full-time care **(Doyle et al., 2024).**

This **high retention rate** confirms and proves the long-term usability of GPS trackers in real-world dementia care contexts **(Doyle et al., 2024).**

Category	Percentage (%)
Alzheimer's Disease Diagnoses	48.8
Mixed Dementia Diagnoses	26.7
Vascular Dementia Diagnoses	17.8
PwD Aged 71-80	53.3

Table 1: Demographics of Study Participants ***(Doyle et al., 2024).***

Of the **34 dyads** that completed the study**, 91%** used at least one GPS feature **(Doyle et al., 2024).**

This included:

- Real-time tracking
- Two-way communication
- Geofencing
- Fall detection

These features enabled caregivers to get alerts when PwD left designated safe zones. The system also proved useful by significantly reducing the need for police assistance in finding lost PwD, as caregivers could quickly share their location **(Doyle et al., 2024).**

The study also showed the financial benefits of using GPS trackers. By delaying the need for PwD to be moved into 24-hour care, local services saved around **£37,000** per person annually. This demonstrates how assistive technology can help reduce the costs of full-time care **(Doyle et al., 2024).**

Moreover, the research by **Qiang et al., (2018)** complements **Doyle et al.'s** findings by highlighting the value of adaptive geofencing. Their research stresses the need for geofencing that adjusts to PwD's routines. This personalized approach helps reduce false alarms and unnecessary interventions, making the system more efficient and improving the caregiver experience **(Qiang et al., 2018).**

2.3 Increasing Independence and Reducing Caregiver Burden

GPS technology gives a major advantage in dementia care by boosting the independence of PwD and reducing caregiver stress. In the study by **Doyle et al., (2024)**, **54.5%** of PwD experienced more freedom due to GPS tracking. It allowed them to move safely in familiar areas while caregivers monitored them remotely. This added independence helped to ease the feelings of confinement and helplessness that often come with dementia **(Doyle et al., 2024).**

For caregivers, the study found a **12%** reduction in stress levels, as measured by the **Zarit Burden Scale (ZBS).** This reduction is significant, as constant supervision of PwD is one of the main sources of stress for caregivers. Knowing that they could rely on real-time GPS alerts and geofencing technology allowed caregivers to feel more secure about their loved one's safety without needing to monitor them constantly **(Doyle et al., 2024).**

Measure	Pre-Trial Score	Post-Trial Score	Reduction (%)
Zarit Burden Scale	40.35 (±12.00)	35.35 (±15.50)	-12%

Table 2: Reduction in Caregiver Burden (Zarit Scale) ***(Doyle et al., 2024)***

To complement this, the findings from **Qiang et al., (2018)**, points out the need for personalized geofencing to further reduce caregiver burden. By learning and adapting to PwD's behavioural patterns, the system can reduce false alarms and minimize the caregiver's need to respond to non-critical notifications. This adaptability will be crucial in the development of the Wandering Detection App to avoid confusions. It allows caregivers to focus on genuine risks rather than being overwhelmed by constant and meaningless alerts **(Qiang et al., 2018).**

2.4 Privacy and Ethical Concerns

While GPS tracking has many advantages, it also brings up ethical concerns, especially around the privacy and independence of PwD. **Doyle et al., (2024)** reported that **30%** of caregivers worried about the possibility of over-surveillance. Constant location tracking could violate PwD's privacy and make them feel like they're losing control over their sensitive personal data **(Doyle et al., 2024).**

Despite these concerns**, 97%** of caregivers appreciated the control over who could access location data, indicating that privacy management tools were a crucial feature for GPS tracking systems **(Doyle et al., 2024).**

To address this issue, a dynamic consent system, as proposed by **Qiang et al., (2018)**, could be a solution. Such a system would allow PwD and caregivers to adjust data-sharing settings in real-time, giving PwD greater control over their privacy while ensuring that caregivers have access to the information they need **(Qiang et al., 2018).**

Moreover, regular consent renewal reminders can help PwD stay in control of their data, reducing the risk of unauthorized access and privacy breaches. **(Qiang et al., 2018; Doyle et al., 2024).**

2.5 User Experience - Challenges and Solutions

Adding to the above, another important factor for the success of GPS tracking in dementia care is how user-friendly the system is. **Doyle et al., (2024)** found that **60.6%** of PwD had trouble using the GPS devices, which suggests that many of these devices are not designed to accommodate their cognitive limitations. Also, **9%** of caregivers mentioned issues with signal accuracy in certain areas, making the geofencing feature less reliable in those environments **(Doyle et al., 2024).**

To address these challenges, the wandering detection app should have an easy-to-use interface. It should have large icons, simple navigation, and voice-activated commands. Offline tracking or backup GPS can be added to keep the system reliable in areas with poor signals **(Doyle et al., 2024).**

The app should also connect and integrate to a solid and well-built smartwatch to track falls and monitor health in real time, along with location tracking. This would give caregivers a complete view of both the physical condition and whereabouts of PwD **(Qiang et al., 2018).**

3. Practical learnings and applications from Existing Solutions

Several companies have successfully used GPS technology to help, monitor and assist people with dementia. For example, **SafeTracks GPS** offers live tracking and geofencing that alerts caregivers when someone leaves a safe area. **Project Lifesaver**, on the other hand, works with local authorities using radio-frequency technology to quickly find those who wander. Another example is **Mindme**, a UK-based company that provides tracking devices with customizable geofencing and emergency alerts for caregivers. These examples show how effective GPS tracking can be in dementia care, reducing the need for police involvement and preventing wandering. By learning from these solutions, the wandering detection app can be further improved to better support both PwD and caregivers **(SafeTracks GPS, 2023; Project Lifesaver, 2023; Mindme, 2023).**

4. Application of the learnings to the Wandering Detection App

Building on the above learnings from the research studies by **Doyle et al., (2024)** and (**Qiang et al., (2018)** as well as from the real-life examples implemented by existing companies, the wandering detection app should implement the below features:

4.1 Adaptive GPS Tracking with Customisable Alerts

An adaptive GPS tracking with customizable geofencing, allows caregivers to set safe zones for PwD. The app must send real-time alerts if PwD leave these areas. By using data mining and machine learning, the app can predict changes in PwD's routines, adjust geofencing, reduce false alarms, and ensure alerts are only triggered for genuine risks. **(Doyle et al., 2024).**

Additionally, **dynamic geofencing** can adapt to different times of the day or locations (e.g., outdoor parks during the day, indoors at night), making the app more practical and suited to PwD's needs. **(Doyle et al., 2024).**

4.2 Improved Caregiver Communication and Support Features

Doyle et al., (2024) found that **58%** of PwD-caregiver pairs used two-way communication to stay in touch. The Wandering Detection App should build on this by offering both voice and text options, making it easy for PwD to reach caregivers when needed. Automated

reminders should prompt caregivers to check on PwD if no movement is detected for long intervals of time, ensuring regular monitoring without adding stress. **(Doyle et al., 2024).**

Functions	No of participant	Percentage
Tracking only	6	13
Tracking, two-way calling only	26	58
Tracking, two-way calling, fall detection alert, geofencing	7	16
Tracking and geofencing only	1	2
Fall detection and tracking only	1	2

Table 3: Features used and the No. of. Participants and their percentage for a specific feature ***(Doyle et al., 2024).***

Emergency Contact List and Last Known Location Sharing: The app should have a feature where caregivers can easily share the PwD's last known location with a list of emergency contacts. This way, if the person goes missing, trusted contacts can quickly help locate them. **(Doyle et al., 2024).**

Direct Link to Emergency Services: The app should also include an option for caregivers to directly contact emergency services when the PwD is in immediate danger or lost. This function could automatically send the person's last location to emergency responders, helping them act quickly. **(Doyle et al., 2024).**

The app should also notify caregivers in critical situations, such as when a **low battery warning** is detected on the GPS device. Integration with a wearable smartwatch would also allow for real-time **fall detection and health monitoring (Doyle et al., 2024).**

4.3 Privacy Controls and Data Management

To tackle the privacy worries raised by caregivers, the Wandering Detection App should offer a clear and easy-to-use privacy dashboard. This would let both caregivers and PwD control who can access their data, allowing them to change permissions or withdraw consent when needed. All location data should be securely encrypted to protect against unauthorized access, and regular reminders to renew consent should be sent to make sure privacy guidelines are followed **(Qiang et al., 2018; Doyle et al., 2024).**

The app should include a dynamic consent system, letting users adjust or revoke data-sharing permissions in real-time. This ensures that PwD can stay in control of their personal

information. These features will strike a balance between safety and the need to respect privacy and independence **(Qiang et al., 2018).**

4.4 Customisable User Experience

Since many caregivers might not be from a technical background and may have specific limitations on a case-to-case basis, the wandering detection app needs a flexible and customizable design. It should include features like larger icons, voice control, and simple navigation to support users with cognitive impairments. For those more comfortable with technology, the app can offer more advanced options, ensuring it caters to a wide range of user abilities **(Doyle et al., 2024).**

The app should consider offline tracking or backup GPS options, such as using Wi-Fi triangulation or cell tower signals, to ensure it functions well in areas with weak GPS signals. This feature is particularly crucial in rural locations or when GPS accuracy is unreliable **(Qiang et al., 2018).**

5. Conclusion

The research report by **Doyle et al., (2024)** demonstrated that GPS trackers can help reduce wandering in people with dementia (PwD), giving them more independence while easing the responsibilities of caregivers. The technology allowed PwD to move more freely, while caregivers felt reassured, which delayed the need for 24-hour care and reduced police involvement in finding lost individuals. However, more extensive research with larger and more diverse groups is necessary to fully confirm these benefits and explore the long-term impacts of GPS tracking in dementia care **(Doyle et al., 2024).**

There were some **limitations** in the study. The small sample size, participants mostly being in later stages of dementia, and the absence of a control group made it harder to draw solid conclusions. Cognitive ability affected how PwD used the devices and how confident their caregivers felt. Additionally, many PwD were unable to complete quality of life surveys, so caregivers had to provide input. Future studies should focus on earlier-stage PwD and explore how GPS trackers can reduce costs related to care and rescue. **(Doyle et al., 2024).**

To make the wandering detection app better, the report suggests adding machine learning to personalize geofencing, improving communication tools for caregivers, and creating a dynamic consent system to balance privacy and safety. Integrating a wearable smartwatch for real-time fall detection and adjusting geofencing for different locations or times of the day will also make the app more flexible **(Doyle et al., 2024; Qiang et al., 2018).**

By addressing these challenges and implementing these improvements, the Wandering Detection App can offer better support for PwD and their caregivers, ensuring safety and more freedom for PwD **(Doyle et al., 2024).**

6.Appendix

6.1 List of Tables

6.1 Key Terms and definitions

Zarit Burden Scale (ZBS): Zarit Burden Scale assesses the stress levels of caregivers, with higher scores indicating greater caregiver burden. It's commonly used in dementia care to evaluate emotional and physical impacts.
PwD: people with dementia
Dyad: A dyad refers to the caregiver-PwD pair used for analysis in studies of shared outcomes.

7. References

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