Experiences of 'Going Out' for People Living with Dementia in Scotland: Findings and Implications for Policy and Practice

A Scottish Justice Fellowship Briefing Paper

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BACKGROUND

Dementia is a term for several diseases affecting memory, language, problem-solving and other thinking abilities, and behaviours that can impact a person's daily life. There are an estimated 90,000 people with dementia in Scotland with over two-thirds living in the community. Supporting people to age in place is vital as formal care services will struggle to meet the needs of the projected increasing numbers of people with dementia (Prince *et al.*, 2014). However, there is a lack of evidence regarding how people living with dementia engage in their community. While being outdoors is an important part of living well and engaging with the community, people with dementia face increased risks when 'going out' of their homes compared to people without dementia. One of these is the increased risk of getting lost and/or being reported missing to the police. Complex cases of people with dementia reported as missing have a high mortality rate, place a high burden on police resources and can result in immense stress for the individual and their families (Perkins, Roberts and Feeney, 2011; Shalev Greene and Pakes, 2014; McShane et al., 1998; Shalev Greene *et al.*, 2019). Research on dementia-related missing incidents has explored newspaper reports, police records or conducted proxy tests (Rowe, 2003; Bantry White and Montgomery, 2015; Algase et al., 2004). Whilst there is research on the lived experience of missing adults, people living with dementia have been excluded from these studies (Stevenson *et al.*, 2013) as it was out of their scope. Research to date related to the lived experiences of people with dementia who live at home has focused on how they feel part of a local community or neighbourhood rather than how they move around their local community areas. Given this gap in the evidence base, this research was designed to draw on novel methodologies that aimed to examine the everyday practice of 'going out' for people with dementia and their care partners who live at home and how they can be better supported to maintain the practice of 'going out'.

RESEARCH APPROACH

This research was guided by three research questions:

1. **How is the experience of 'going out' for people with dementia and their care partners?**
2. **How does 'going out' impact people with dementia's sense of independence, agency and control over their lives?**
3. **How can we support people with dementia to maintain the everyday activity of 'going out'?**

This research employed walking interviews[1], traditional interviews and group discussions with 19 people with dementia and 19 care partners across Scotland. Fieldwork took place in rural, semi-urban and urban settings across Scotland from December 2018 until September 2019. Walking interviews ranged from a 20-minute walk around the local village to spending several hours together, hiking local trails, going to charity shops, and stopping for lunch or coffee in local cafes. Consent was obtained through a method of process consent (Dewing, 2008) which was a continuous process using the researcher's subjective analysis of the participant's capacity to consent. The data were analysed using a combination of qualitative methods including reflexive thematic analysis (Braun and Clarke, 2019) and thick narrative descriptions of the walking interviews.

KEY FINDINGS

Theme 1: Making Adaptive Decisions to Maintain Independence

This research found that participants who were living with dementia were active agents in the practice of 'going out.' In other words, when people living with dementia 'go out,' they are continually making decisions and weighing up the risks versus benefits. As dementia is a fluctuating condition, people are constantly renegotiating what they are capable of. This adaptive decision-making enabled participants to maintain a sense of freedom and independence:

'I've been brought up in a free society, I've been brought up to believe it is our human right to be free, our human right to make choices. And if I want to go out I should have a right to be able to go out.'
(Maria, living with dementia).

Theme 2: The Relational Agency of 'Going Out'

Although participants advocate for their rights to freedom and independence, they acknowledged that for these rights to be fulfilled, support from others was required. This support came in many forms, but it was dependent on both parties accepting the constant shift in the dependence dynamic between them. Almost every participant carried a dementia ID card and expressed a willingness to ask for help if lost. Although some considered revealing their diagnosis to strangers to be a risk to their sense of safety, it was ultimately a risk worth taking if it meant they received the necessary support:

'The short answer is I would ask for help, I've got my little dementia ticket on. And I wouldn't have any qualms about showing that and explaining the situation.'
(Laurence, living with dementia).

1 Walking interviews are a mobile method often used in place-based research. They are a flexible, inclusive and contextually relevant method that combine both interview and observational methods.

Theme 3: Feeling Part of a Place

For the purpose of this research, place is understood as both an abstract concept where daily lives are lived and a physical landscape. Through exploring place as a physical environment, this research attempted to bridge the messy middle ground between participants' experiences of 'going out', getting lost and being missing, highlighting how people living with dementia are active agents in making decisions and in navigating the environment. Being connected to nature was an important way for participants to feel part of a place. Participants also went out to maintain a sense of belonging to a place and to feel a part of their local community:

'If you don't show up, they miss you, wondering if you're okay.'
(John, living with dementia).

'Going out' gave people a sense of purpose and completing the task gave them a sense of accomplishment, which allowed them to feel like active citizens who were participating in the social economy.

Theme 4: Challenges and Coping Strategies

The physical environment presented both challenges and opportunities for participants to maintain agency whilst 'going out'. Navigation became more complex when the environment changed or depending on how familiar it was. However, participants used features of the environment and place-based strategies to navigate and overcome these challenges. Participants' experiences of 'going out' were impacted by challenges in the environment such as changes in weather, roadworks and construction, and familiarity of the environment. These challenges could impair participants' ability to navigate:

'A change, any sort of change. Knock down a building, even knocking down a tree, I'm going along, and suddenly they've knocked the tree down overnight, it's changed the picture in your mind, you don't recognise it. So, and again, if they put up a, sometimes they can put up buildings within weeks, a new building appearing. So, you think to yourself, this isn't the road I'm going, this isn't where I should be.' (Laurence, living with dementia).

Putting the Findings in Context: The 3 P's - A Heuristic Tool to Understand the Motives and Strategies of 'Going Out' for People Living with Dementia

It is important to note that dementia is not one disease with one set of symptoms. The diversity in participants' experiences of 'going out' highlights how dementia can impact each individual differently. Therefore, responses to missing incidents need to be personalised to the individual. In order to aid this personalised approach, a heuristic tool has been developed based on the findings of this research (Figure 1).

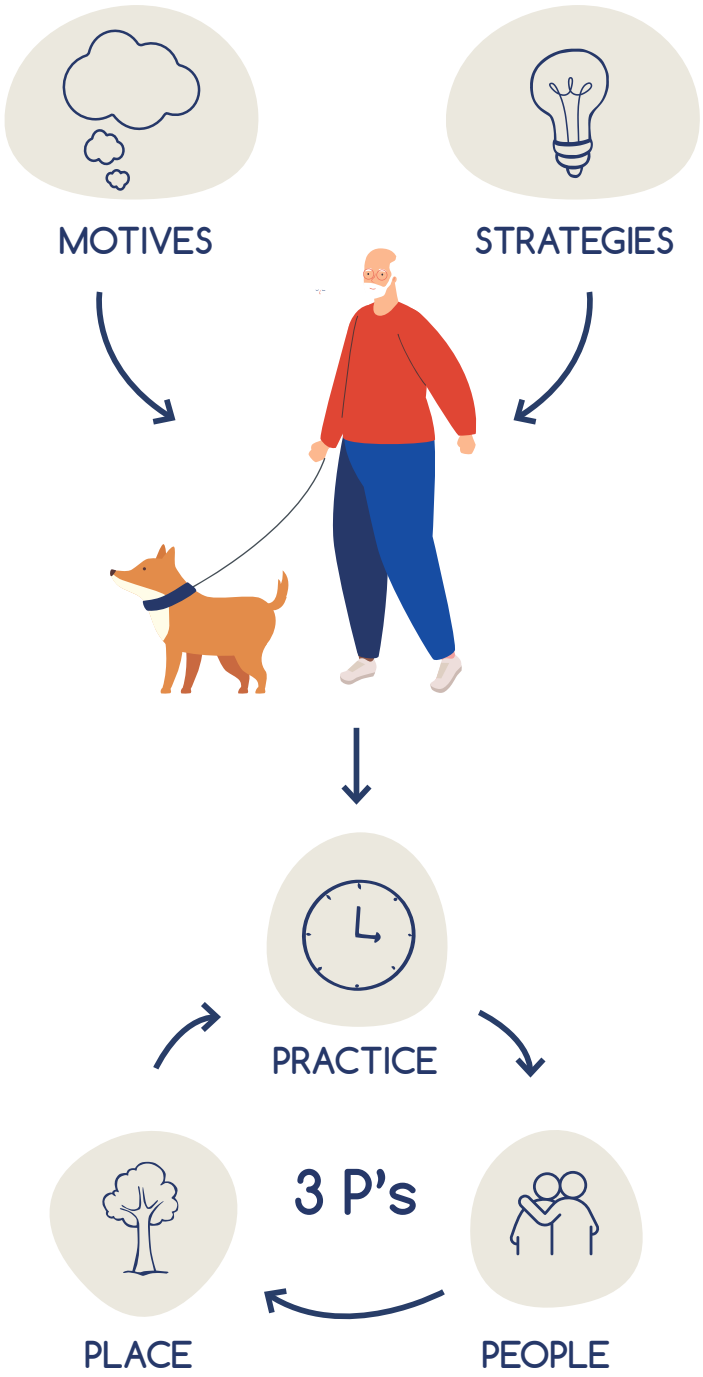


Figure 1. The 3 P's: A heuristic tool to understand motives and strategies for 'going out' for people living with dementia

In order to understand what happens when people with dementia become lost or are reported missing, we must first ask the questions "why do people

living with dementia go out?" and "how do people with dementia go out?" Answering these questions helps us to understand an individual's motives and strategies for 'going out'. To further hone these questions, the findings of this research support the examination of a person's practices, the places they go and the people they engage with to add an individualised context to their experience of 'going out'. These practices, places and people are the 3 P's.

The central premise of the 3 P's is that the person living with dementia should be at the heart of decision-making regarding 'going out'. This is represented visually by a picture of a woman walking her dog in the centre of the diagram. Practically, this diagram can be used by people with dementia and their families in advanced care planning, and as a self-management tool to prevent potential missing incidents. It can also be used by search and rescue teams to guide search strategies by the collection of appropriate background information when a person with dementia is reported missing. It is especially useful in the latter context as it shifts the narrative away from labelling people with dementia as one homogenous group whose movements can be categorised, toward a person-centred approach where an individual's motives and strategies are understood in the context of sociocultural factors.

IMPLICATIONS FOR POLICY AND PRACTICE

Dementia Policy Implications

At a policy level, Scotland's National Dementia Strategy 2017-2020 committed to considering the recommendation of a Police Scotland Missing Persons Report regarding people with dementia (Scottish Government, 2017b). Therefore, this research is timely as it provides evidence that this commitment should be taken further and expanded to consider working with non-government partners and prioritising the voices of people living with dementia to ensure they are adequately supported to live independently at home.

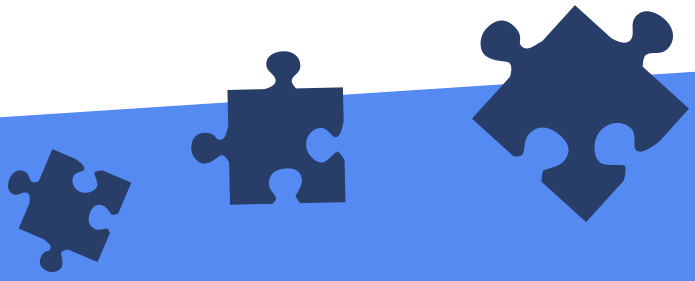
The findings of this research support the shift in dementia policy focus towards an early diagnosis, a focus on prevention and supporting person-centred care. However, in a policy context, there should be a wider consideration of aspects of living with dementia beyond cure, diagnosis and formal care. By developing a better understanding of the practices of daily life for people with dementia and the places in which they are carried out, people living with dementia can be better supported to remain integrated within their local communities. This aligns with one of the intended outcomes of Scotland's National Dementia Strategy 2017-2020; that there are more dementia-friendly and dementia-enabled communities, organisations, institutions and initiatives.

Missing Persons Practice and Policy Implications

This research found that people with dementia use strategies to navigate their environment, to prevent getting lost and to relocate themselves when lost. These strategies include the use of landmarks, the familiarity of an environment, using pre-agreed routes and asking for help, and changes in the environment. Although previous attempts have been made to profile the behaviours of missing persons, there is limited evidence that examines people's experiences of being missing (Parr and Fyfe, 2013). In line with the National Missing Person's Framework's aim to prevent missing episodes, this study provides evidence for the need to:

- acknowledge people living with dementia as a unique (but not homogenous) group who are impacted by missing incidents, and
- to support and value research that platforms the voices of those who are impacted by missing.

The framework addressed people living with dementia specifically and acknowledged the importance of understanding why a person goes missing in preventing reoccurrence. Although this framework is welcome, it places people with dementia in the category of 'unintentionally missing', which does not accurately represent the experience of dementia and missing.



CONCLUSION

This research brings a more person-centred, social citizenship lens to the predominantly biomedical field of dementia and missing research. In doing so, it argues against the categorisation of dementia-related missing incidents as one homogenous group. This is because dementia is not one disease with one set of symptoms. Overall, this study argues that by shifting attention away from the general narrative that tries attempts to define the 'problem' of missing, getting lost or wandering in dementia and onto understanding people's motives and strategies for 'going out', we can view people with dementia as active agents who make decisions rather than a problem or behaviour to be managed.

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The full research thesis from which this briefing derives is freely available online: https://era.ed.ac.uk/handle/1842/39074

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