Walking interviews with people with dementia: experiences of going out, navigating and getting lost.

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Background

Out of doors mobility is an important part of living well with dementia (Bantry White & Montgomery, 2015).

Poor topographical memory leads to poor navigation and increased risk of getting lost (McShane et al., 1998). Therefore, people living with dementia are at risk of becoming lost even in familiar environments (Rowe & Bennett, 2003).

The individual may or may not feel like they are lost.

Despite their elevated risk, the majority of people with dementia who go missing are found safe and well. Concern about missing leads to preventative measures.

High complex cases have a high mortality and morbidity rate, place a high burden on police and search teams, and results in immense stress for families and individuals themselves.

In Scotland, 2% (538) of investigations involved someone with dementia (Police Scotland, Missing Persons Annual Report 2017/2018).
Research Aims

• To understand the experience of 'going out' and potentially being 'missing' for people with dementia and their families
• How people with dementia negotiate this experience and how it affects their independence, sense of identity, control and purpose
• How can we facilitate people with dementia to 'go out' safely?
Research Design

Focus Groups
- Six in total
- One with carers
- Four with people with dementia
- One with carers and people with dementia

Walking Interviews
- Aiming for fifteen total participants
- Meeting each participant up to three times

Family/ Care Partner Interviews
- Aiming for fifteen total participants
Why walking interviews?

Using a combination of interviews and observations have been recommended when doing qualitative research with people with dementia (Nygård, 2006).

Traditional user involvement can exclude people with dementia and they may need more support (Brooks, Savitch, & Gridley, 2016).

Therefore, we have to be more creative. We must have a more flexible attitude towards consent and use a wide range of ways of engaging with people with dementia.
**Ability can fluctuate**
“I have good days and bad days”
“This wee book rules my life”
“The next time you see me, I’ll probably have one of those tracker things around my neck”
“I don’t go to unfamiliar places”

**Changes in environment**
“Things like scaffolding can really throw me”
“Cut down trees can be disorientating”
“Uneven surfaces affect my balance”

**Resilience and coping strategies**
“I try not to drive at night anymore”
“I walk along the same route”
“I time him”
“This wee book rules my life”
“The next time you see me, I’ll probably have one of those tracker things around my neck”

**Other people’s reactions**
“There’s still a stigma”
“I find people very intimidating now…I’ve lost trust in people”
“I’m not confident using the bus because drivers pull away before you can sit down”
“I’m careful about who I ask for help…Someone in uniform or wee old ladies are best”

**Signage and landmarks**
“The signs for men’s and women’s toilets start to look so similar”
“Simple things like black writing on a yellow sign make such a difference”
“Aha! There’s the church. I know where I am now”

**Sensory impairments**
“That lift can look like a black hole”
“When I’m in the car it feels like everything is coming towards me…I have to close my eyes”
“It all started when he was having problems with his vision”
Case Study: Jim

Context

• 65 year old retired male with dementia
• Lives at home with his wife who works part-time
• Had a career in the army and emergency service planning
• Is still driving
• Loves walking and goes out on his own every day
• Very socially active

Challenges Encountered

• Driving- forgetting where he parked and disorientation when driving
• Getting lost and being missing- was reported missing by his wife once
• Concerns around his memory
• Sensory impairments- didn’t see a car coming because it was a dark colour, the same as the road
Case Study: James

Strategies Described

• Driving- changed to a simpler car, no longer drives at night or in bad weather
• Getting lost- sticks to walking paths, is getting a tracking device
• Memory problems- keeps to a strict routine

Lessons Learned

• Although James was never lost, the ‘missing’ episode was still traumatic and has lasting impact on him and his family
• We cannot assume that every dementia case involves someone who is lost or had gone ‘wandering’
International Consortium for Dementia and Wayfinding

A multiagency global platform
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Thank you for listening!

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References


