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Getting lost with dementia: Encounters with the time-space of not knowing

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A B S T R A C T

In this paper we explore the experience and implications of getting lost with dementia. While getting lost has become culturally emblematic of dementia, speaking as it does to a widespread fear of losing our place in the world, it is marked by an overall absence of critical attention. We argue that this critical hesitancy is part of a broader unease with ‘dementing’ that reveals a paradox in dementia scholarship as growing emphasis on strengths-based and capacity-oriented approaches to the condition shift attention away from episodes of disorientation, forgetting and unknowing that commonly arise after onset. We therefore explore getting lost with dementia, not only as a route to better understanding what happens during such events and the meaning it holds but also to consider the implications for a broader politics of the social inclusion of people living with dementia. Reporting findings from a five-year international study of the neighbourhood experiences of people with dementia, we suggest that through such experiences as getting lost, people with dementia have a unique and distinctive contribution to make to the ever-evolving character of public space and civic culture. In particular, we argue that getting lost and the subsequent recovery or reconstitution that ensues can help inform efforts to reimagine public space. This includes looking beyond risk reduction in responses to dementia and public and outdoor settings to consider how freedom of movement for people with dementia might be enhanced rather than curtailed. Our learning points to the value of making the process of dementing more visible and central to the politics and practices of social inclusion.

1. Introduction

Getting lost is a disruption not only to the relationship with our surroundings but to continuity in our sense of self and habitus. Either voluntarily or unintentionally, it involves relinquishing control as the unfamiliar overtakes us. Lather (2012) suggests that getting lost can involve trading confidence and certainty for the possibility of new knowledge and even new ways of knowing. It can also serve as a reminder of the fragility of in/dependence (Schillmeier 2008). Through close observation of people with dementia admitted to residential care, Örvulv, 2014 has argued that what matters to individuals who feel lost is a deficit in moral agency, expressed through a struggle to place themselves and find purpose in an environment that is hard to decipher. From this perspective, getting lost might be less about geography and more about identity (Solnit 2006).

As dementia care and support migrate from institutional settings to the community, so the event of getting lost *with dementia* is becoming woven into everyday neighbourhood life. Missing persons appeals in

mainstream and social media (MacAndrew et al., 2018; Rowe and Bennett 2003) have made getting lost both more visible and proximate. Across diverse genres, a raft of recent films: (Still Alice (2015); Finding Dory (2016); The Father (2020); Supernova (2020); Relic (2020)) and TV soap opera storylines (for instance in the UK, Emmerdale (2016)) have each sought to trace the experience of getting or being lost and its association with memory loss or cognitive change. While not always depicted from the perspective of the person with dementia, collectively such portrayals suggest that getting lost is becoming culturally emblematic of dementia. Indeed, much in the way that Katz (2011) has described a fall in later life as coming to define the faller, so getting lost has particular consequences for those with cognitive impairment. A person's claim to autonomy and independence can subsequently be thrown into question, heralding restrictions upon their freedom of movement.

Yet, getting lost with dementia is an experience marked by an overall absence of critical attention. Much research in the social sciences and humanities has unquestioningly adopted the event of getting lost as a

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category of experience associated with dementia (Silverstein et al., 2006). This has foreclosed further examination while leading to a focus upon strategies to minimise risk through surveillant technology (Bartlett et al., 2019; White et al., 2010) and design of the built environment (Feddersen and Lütke, 2014). Such critical hesitancy points to a broader unease with what Schillmeier (2014) refers to as ‘dementing’. This reveals a paradox in recent dementia scholarship as growing emphasis on strengths-based and capacity-oriented approaches to the condition (e.g. Gaber et al., 2022; Vernooij-Dassen and Jeon 2016) shift attention away from episodes of disorientation, forgetting and unknowing that are common to the experience of dementia.

In this paper we draw upon Schillmeier’s (2014) explication of the social and political significance of ‘dementing’ to explore both the experience and implications of getting lost with dementia. At the heart of Schillmeier’s argument lies a call to focus on what he terms the ‘process of dementing’:

That is the process of forgetting, of intensive feelings, of being affected by an unknown world, of confusing things, of feeling lost, of being misunderstood, of feeling displaced, of lacking a voice, of being different than expected, and so on’ (p.35).

Part of the significance of ‘dementing’ is that it points to new and different ways of being and knowing. It thereby provides a standpoint from which to critique current conditions, illuminating the assumptions and interests that shape our social, political and material worlds. Our aim in this paper is not only to better understand what happens when someone gets lost and the meanings it can hold, but to consider the implications for a broader politics of social inclusion and the constitution of public space.

2. Background

In biomedical terms both temporal and topographical disorientation have long been considered symptomatic of dementia and indicative of the presence and severity of cognitive impairment (O’Keeffe et al., 2011; Pai and Jan 2020). Getting lost has been anchored neurologically through research into deficits in visuospatial and visuo-perceptive processing, medial temporal atrophy and damage to the hippocampus. Evidence points to a combination of disorientation, difficulties in maintaining directed attention (distraction) and in envisaging/-remembering a route map as variables in such events (Chiu et al., 2004; Pai and Jacobs 2004, Yatawara et al., 2017). Originally associated with wandering (itself defined as a behavioural category), subsequent studies have argued that ‘getting lost behaviour’ is a separate and distinctive symptom. In the case of Alzheimer’s Disease, it has been identified as an early sign of cognitive impairment (e.g. Guariglia and Nitrini 2009; Rowe et al., 2011). As such, getting lost is both an outcome of dementia and an indicator of it, located at the level of the individual and more specifically, attributed to changes in the brain. Furthermore, biomedically framed research omits attention to the experience and perspectives of people with dementia, in some cases actively excluding direct input on grounds of unreliability (e.g. Pai and Lee 2016).

A critical silence surrounds what people actually go through when they get lost. Little is known of the changes in and to a person’s relationship with time and place, the sensory, affective and emotional dimensions to this shift, or of how a person makes sense of this. Instead, research has foregrounded questions of risk through a focus upon prevalence and the frequency at which a person gets lost, which appear to vary across studies according to method (e.g. White and Montgomery 2015; Bowen et al., 2011; Pai and Lee 2016). McShane et al. (1998) considered outcomes, revealing a person with dementia who gets lost (sometimes only once) was often subject to increased levels of surveillance and restrictions to their movement outside the home. Getting lost also correlates with increased liability for admission to long-term care. And yet, secondary analysis of missing persons reports and media coverage of dementia-related ‘missing incidents’, reveal their heterogeneity. Rowe et al. (2015) point to a mix of contextual, situational and

neurocognitive antecedents, while noting that many individuals are found shortly after going missing or return home of their own accord. White and Montgomery (2016) extracted data retrospectively from missing persons reports over a period of 4 years finding that less than 5% of people came to serious harm, identifying 2 deaths out of 281 reported incidents. Their analysis showed that the type of environment (i.e. rural, isolated) and environmental hazards such as bodies of water or dense bushland played a significant role in how quickly a person is found and the degree of risk involved. There is then a tension between this diversity of reported incidents and the homogenising (and individualising) effect of classing getting lost as a singular category of behaviour.

Toward the end of the last century, the emphasis in research shifted to a concern with wayfinding in public and outdoor spaces (Sheehan et al., 2006). Findings suggested that urban design could support orientation and independent movement of the person with dementia (Blackman et al., 2007; Marquardt 2011). However, the focus on wayfinding with dementia also narrowly defined the experience of public space around questions of navigability and legibility. It downplayed the complexity and multiplicity of relationships to place, resting upon the assumption of an essentialised experience of dementia. Rather than disrupting biomedical categories, research treated design as a means to alleviate pre-defined symptoms and compensate for deficits (Barrett et al., 2019; Day et al., 2000). Efforts to identify ‘dementia-friendly’ design principles (Burton and Mitchell 2006) reinforced a view of dementia as an abstract collection of characteristics and losses (Heylighen and Bianchin 2013), consistent over time and space. This has driven policy-based assumptions that pre-determined interventions will lead to knowable outcomes for people with dementia (Ceci et al., 2020).

More recently dementia scholarship has turned to consider the ‘agentic person’ (Poland and Birt 2016), via a call to focus upon the ‘remaining capacities’ of people living with dementia, including their potential for resilience and adaptability. Informed by positive psychology, collectively this work offers a counterweight to a ‘loss-deficit paradigm’ through a shift in focus to questions of hope, reciprocity and flourishing with dementia (de Vugt and Dröes, 2017; Wolverson et al., 2016). However, in this paper, we sound a note of caution in respect to this emerging emphasis on capacity, capability and ultimately upon citizenship (e.g. Mitchell et al., 2020; Martyr et al., 2018). Rather than problematising or deconstructing biomedical categories, we argue such work merely shifts the locus of attention. This has meant the analysis and understanding of the process of ‘dementing’ has been largely abandoned to a biomedical framing. We suggest such an approach poses a dilemma for dementia policy and practice: How can we reimagine and reconstitute our social and material surroundings to enhance inclusivity, if the focus for dementia research is upon sameness, and the downplaying of difference?

Schillmeier (2014) observes that a social science response to the biomedical paradigm has sought to underscore shared attributes and capacities, such as individual agency, that have been previously denied or unrecognised in people living with dementia. He argues this is a partial and ultimately exclusionary approach to the recognition of people with dementia: ‘Clearly, the *dementing* person, the one caught by the moment of dementia, the one who can’t remember, who doesn’t know, who is paralyzed by uncertainties and anxiety, who remains silent and cannot write, the one who cannot speak out and so on, does not get a political voice’ (p.35). Ultimately, then, Schillmeier’s argument is for making the process of ‘dementing’ central to the politics and practices of social inclusion.

We acknowledge what will be for some the jarring nature of the term ‘dementing’, given the potential for medicalised language to reinforce the othering of people living with the condition (e.g. Sabat et al., 2011). However, we note the absence of alternative (non-medicalised) terminology specifically for drawing a distinction between ‘dementing’ as a situated event and ‘dementia’ as a diagnosis or condition that supposedly transcends time and place. We suggest getting lost can be approached in a political (and agentic-focused) way, by asking how it

might inform efforts to transform public space and civic culture.

3. The research

The 'Neighbourhoods: our people, our places' (N:OPOP) study (2014–2019) was itself undertaken as part of a wider programme of research exploring dementia and neighbourhoods (Keady 2014). Our aim was to investigate how neighbourhoods can support people living with dementia to remain socially and physically active. This international, qualitative study combined a longitudinal and comparative design, and was rooted in a constructivist paradigm. The project extended over three fieldsites: Greater Manchester in northern England; the Central Belt of Scotland; and the county of Östergötland in the south of Sweden. There were two points of data capture of between 8 and 12 months apart and a total of 67 people with dementia and 60 carers participated in 304 in-depth interviews.

In the UK fieldsites, social network mapping provided opportunities to explore the different types and sources of support offered to the participants while understanding their role in supporting and caring for others (Campbell et al., 2019). We also asked participants to give us a tour of their home, which we filmed or audio-recorded according to their preference. In both the UK and Sweden, we used walking interviews to find out how the person with dementia defined their neighbourhood and the places of importance within it (Odzakovic et al., 2020). We approached the mapping exercise, the tour and the walks as elicitation opportunities, engaging the participants throughout in conversation, probing their commentaries. For each method we transcribed these discussions, with the transcripts serving as the focus for subsequent analysis, enhanced by what we had learned from the research encounter.

4. Situating dementia as a methodological challenge

The methods combined to support a multi-faceted understanding (Mason 2011) of neighbourhood life for people living with dementia. While network mapping situated people relationally the walking interviews offered insights into the situated production of knowledge, as we observed people moving through the local environment while discussing it. Through mobile methods we engaged with the performativity of knowledge (Pink 2012) learning how a person's relationship to place is enacted as well as articulated. In-situ interviewing provided environmental cues and prompts to recollection that would have been unavailable through conventional sedentary interviewing. This supported participation in the interview process and enabled the person with dementia to lead the research encounter, making decisions about where we went and what was noteworthy. Mobile methods also offered glimpses beyond the 'constructedness' of the interview exchange as we witnessed and shared a more directly embodied and multi-sensory relationship to the environment. We were further able to observe how people managed unexpected events and social encounters; the potential challenge of environmental features like roads or the bustle of the high street. Crucially, as we come on to reveal, mobile methods offered a different way of encountering the empirical world. The methodological challenge lay in engaging with what Sumartojo and Pink (2018) describe as the 'ongoing-ness' of everyday life, where researchers must:

Work in a way that is emergent and processual and that does not seek to define or presuppose particular outcomes. Instead, we must build our knowledge step-by-step as we come to make sense of how other people experience the world, how these experiences come to have meaning and what these meanings are. (p.11, 2018).

5. Findings

The majority of the people living with dementia recruited to the study mentioned experiences related to getting or feeling lost. For the purposes of this paper, we have focused on a sub-set of participants who

chose to describe and discuss the experience in greater detail. In this section we draw out four dimensions to participants' accounts of getting lost as situated, emergent, evolving and heterogenous.

6. The situatedness of getting lost with dementia

We found that getting lost often arose out of the way dementia is configured in time and space. For instance, Sean recalled: *I've got lost in familiar places. Take the example of the doctor's, I've been going there 20 odd years. And a couple of times I've went down [road name] and I don't know where I am. So, I get my help card and ask, you know, where it is.* For Sean, there seems to be no internal drama unfolding here, at least not in the retelling. He makes clear that getting lost is a situated event, it has co-ordinates and a duration, albeit of an unpredictable nature. In his account we can see the resulting fragility of independence, but also how its erosion isn't necessarily an assault upon his sense of self. Now in his 70's, Sean had been diagnosed with young onset vascular dementia over ten years earlier. He had become accustomed to uncertainty as a feature of the relationship to his neighbourhood. Like many others we spoke to, he countered this by always following the same route from his home to the local high street where he spent much of his time. Sean's experience echoed the way many other participants described their experience of dementia, not as a continual presence in their lives but rather as points of intrusion that shift and disrupt their relationship to place.

For others, getting lost incited fear, sometimes a paralysing sense of panic. Ruth recalled one of the first times she had got lost: *'You can understand the panic, you can understand why because I was hysterical by the time they [police] got to me, I mean, I don't do hysterics. I was so, 'my god', and 'I'm not in control' and 'am I stupid? Is this my life? Am I going to be like this all my life? I can't go out anymore' [...] and it would have been nice if someone would've said, 'you know, this is a blip'. But they didn't.'* Ruth's recollection makes clear both an affective dimension to getting lost and the meaning-making that surrounds such events. After relocating in early adulthood, Ruth had returned to live in the neighbourhood where she had grown up. She knew the area intimately but had found her way into a new-build housing estate and suddenly become disoriented. While the incident occurred some years earlier, not long after receiving a diagnosis of young onset Alzheimer's, Ruth clearly recalls her own sense of an unravelling self and the intense uncertainty this brought upon her. Sandra similarly felt plagued by what she described as 'blips', as illustrated on one occasion when out driving alone: *I lost 2 hours from leaving the house to realising I didn't know where I was or what was going on or how to drive the car. I didn't even know how to get out of the car. So luckily then I rang the last number dialled and it was [husband]. Well apparently, I said 'do you know who I am?' And he was like 'well, yeah, do you know who I am?' And I said I didn't know who I am, I don't know where I am, I don't know what's going on'.* Sandra, now in her early 60's, was abroad when this incident occurred although driving through an area she knew well, having lived there a number of years. The experience had influenced her decision to return to the UK, where she had subsequently been diagnosed with vascular dementia. What is striking about the episode as she describes it, is less the fact of losing her way and more the sudden decomposition of identity and selfhood that accompanies it.

Schillmeier (2014) argues: 'it is precisely the 'passing fright' of the moment of dementia itself that opens up a time-space of not knowing what is happening, and not knowing what to do about it' (p.40). Sandra's experience draws questions about what it means to inhabit this time-space of not knowing and the implications for how we conceptualise a person's relationship to their world. Sandra's husband subsequently kept her on the phone while she described her surroundings until a friend was able to locate and collect her. Notable to the aftermath of this 'passing fright' was the nature of Sandra's recovery; the assemblage of technology, people, and things alongside her own efforts at self-composure over a period of what she estimated to be about 4 hours. This is equally significant to our understanding because research to date

has cast getting lost as that moment (i.e. a snapshot in time) when a person's relationship to the world deconstructs betraying evidence of deficit and impairment. Yet, our analysis points to a durational conception and the importance of attending to subsequent reconstitution as the onflow from such dementing episodes.

6.1. An emergent relationship with place

Elsewhere (Clark et al., 2020; Ward et al., 2021), we have argued for the value of a relational understanding of neighbourhoods in a context of living with dementia. This builds on Massey's (2005) temporal conception of place as moving forward in time, captured by her notion of the 'place-event'. From this perspective, the unpredictability of our (near-future) relationship with place is inescapable and crystallizes in the moment of getting lost. The findings reveal that this emergent relationship with place often sparks friction as care partners foreground avoidance of risk over freedom of movement. Clarke et al. (2010) have thus proposed an understanding of risk as 'contested territory', where much is at stake for the person with dementia.

We interviewed Suzanne (in her early 60's), about three years after the receipt of a diagnosis of young onset Alzheimer's. She had lived in the same home for more than 25 years on a suburban street on the edge of a large city. It was an affluent area, and a place of natural beauty where Suzanne cherished being outdoors. During our walk together she spoke of her passion for running but also her fear that getting lost could curb her future movement:

I'm dreading it happening because if it does happen I'm duty bound to tell [husband] and he's going to say 'that's it, you're not running on your own anymore'.

I: So, your independence is resting on that, kind of?

S: Yes, absolutely because I haven't got any independence at all really, apart from running because he does everything, even to put my clothes out and helping me dress, because that's a problem now.

Suzanne's husband's response, like that of many care partners and practitioners is to treat future uncertainty as requiring containment. Yet, Suzanne herself is far less worried about the prospect of getting lost than of losing a last vestige of independence. Without wishing to downplay the potential for harm associated with getting lost, we argue for recognition of how people with dementia themselves are problematising the orthodoxy of risk aversion, often as the de facto response to dementia. This means we should be asking how experiences of uncertainty and unknowing might shape the way we envisage the future of public space. Could uncertainty lead to beneficial outcomes, or simply *not* pose a threat? Might it be embraced or accommodated to enhance rather than curtail freedoms?

The care partners we spoke to were often clear that restricting movement and/or introducing surveillant technology such as GPS tracking, was for their own peace of mind. Gayle spoke of being 'panic stricken' in the period following Murray's diagnosis. She insisted he wore a tracking device and installed a camera in the home so she could check on his welfare while at work. An emphasis on risk had reordered the couple's relationship with very real consequences for Murray's freedom. During a joint interview, Murray used humour to signal his resistance to these measures, describing Gayle as his 'prison governor' 'jailer' and 'stalker'. We can read Murray's half-joking retorts as an indicator of the complexities of self-assertion in a context of relying on someone else for support. In this respect, Akama et al. (2018) note that risk often decides 'who is allowed to act or speak in the face of uncertainty' (p.31). We witnessed this repeatedly in the tensions between people with dementia and their care partners (sometimes also practitioners).

For others, being positioned as vulnerable and at risk led to efforts at reclaiming and recasting their experience of dementia (Ward et al., 2021). For instance, during a walking interview Brendan related epic stories of getting lost, citing an airman surviving in the wilderness after a plane crash and the heroism of an Alaskan fisherman who trekked for

miles before finding civilisation. Meanwhile, George was keen for us to see that getting lost had not disrupted his sense of belonging or comfort in public spaces, even suggesting an openness to uncertainty: *I've got lost in some places purposely, I went certain places to get lost. Because I looked at it with a clear vision, I had no inhibitions about anything at all [...] And I'd take my camera, or my sketch pad and I would sketch and do some drawings, and I met hundreds of people.* Later, George relayed how he would advise people newly-diagnosed not to panic if they became lost, but to relax, even enjoy the experience and to embrace a state of unknowing.

George's efforts at dissociating uncertainty from the affective threat of risk suggest there might be alternative ways of facing the indeterminacy of the near-future neighbourhood that refuse to be framed by a discourse of risk. Risk has long been central to the interpretive framing of dementia, overshadowing the possibility of approaching uncertainty as anything other than a threat. We saw the outcomes of this in the perspectives shared by many care partners who articulated the weight of responsibility they felt for anticipating potential risk. Such conditions leave open to question how place-based responses to dementia might seek to engender spaces where uncertainty is no longer funnelled into surveillant practices, containment and the loss of freedom. Altered relations with place through experiences of forgetting or unknowing may indeed lead to 'more creative, more cooperative, more surprising ways of being in the world' (Halberstam, 2011, p.2), but an aversion to risk too frequently pre-empts such possibilities.

7. The evolving repetition of getting lost

For participants who had lived with dementia for some time, getting lost had become a known hazard. But, while it was a repeated experience this did not mean the same thing reoccurred. Deleuze (1994) has argued that repetition is difference in the sense that each moment of repetition is always unique; conditions never realign in exactly the same way. We heard how various participants inevitably learned from each getting lost event, interpreting and adapting themselves over time. So, while it may be impossible to entirely avoid getting lost it was certainly possible to prepare for it and respond differently. Dennis explained: *Now, I've always taught myself that if I get into that panic situation I stand where I am and wait for someone that I can speak to rather than thinking well I'll go that way, just try and find my own way.* In some cases, people had begun to gather a small collection of items in the face of this known uncertainty. Sandra, now living in a warden-supported apartment in a high-rise block in a busy urban area, noted: *I used to have a list of things in my bag I needed to take, but now I do it by rote. So, I know I take my telephone, I take my hearing aid batteries in case my battery goes and they're always in my bag. I must make sure I've got them and my purse. I always make sure I've got my bus pass and my purse.*

We learned that some people had developed preparatory rituals ahead of leaving home, not only double-checking doors, windows, oven etc. but also gathering various aids to alleviate the trepidation associated with the near-future neighbourhood. Ruth (who lived alone) was one of a number of participants who walked us through her routine, which had evolved through learning from past experiences of getting lost. She collected money, medication, phone, travel pass and a card that she could show people which explained her diagnosis. Her preparatory practices bridged leaving the home and journeying through the neighbourhood, facilitating a transition from the no longer to the not yet. Such processes of interpretation and adaptation show that it is impossible to disentangle the history, cumulative knowledge and disposition that people bring to an event such as getting lost from any notion of impairment. Indeed, far from fixed and knowable, impairment itself is defined through a broader series of configurations and is often felt to be discontinuous. While people's responses to getting lost varied widely, from phoning a friend, asking help of a passer-by, calling a taxi, retracing their steps or following home the family dog, these practices revealed the inherently relational and situated nature of their response.

8. The heterogeneity of getting lost

Our findings point to the multiplicity of experiences elided under the banner of getting lost; not only in terms of how dementia intersects with other aspects of identification or social location to shape interpretations of place, but also how such events are explained and by whom. For some, getting lost was attributed to a slowly descending internal fogginess, sometimes a more sudden change. Vanessa spoke of *'a switch in my brain it just shuts off and I can't do anything'*. For others, it was reported to be triggered by an externalised event, a new environment or change to an otherwise familiar situation. We learned that some people get lost due to exhaustion associated with navigating public space or because of a hectic or over-stimulating setting. In other cases, someone feeling unsure of where they were had become a more enduring aspect of their relationship with place. Grace, who had migrated from the Caribbean in her youth, asked a number of times for confirmation of where she was currently living during our walking interview, even though the walk itself circled the block where her apartment was located.

Getting lost could be contentious, sometimes a matter of standpoint or perspective. As for instance, when someone didn't see or feel themselves to be lost but were considered so by family or service providers. Siobhan recalled a telephone call from her mother's home care agency to report Kathleen as lost after being left sat outside her home while her care worker was busy inside. Kathleen still lived in the same home where she had raised her family and had an intimate familiarity with the surrounding area. Her mobility was now limited, and she walked with the aid of a rollator, requiring support to leave her home. Nonetheless, Kathleen had intentionally set out on her own, heading to the local swimming pool (Siobhan believed) and was soon traced. In the same interview Siobhan had relayed the tightly timed nature of her mother's home care, focused on meal preparation and personal care but without any support for Kathleen to leave her home, where she now lived alone.

Kathleen's 'getting lost' episode, as recounted by her daughter, underlines how the under-timing of care provision disallowed opportunities for leaving the home, instead focusing narrowly upon a pre-determined set of care tasks. Kathleen's isolation at home and her desire to escape were a product of a care system that ranks instrumental support with 'basic activities of daily living' (BADLs) over participation in the wider neighbourhood. Tellingly, the formal response to the incident by the care agency prioritised risk avoidance. Surveillance of Kathleen's movements was heightened by doubling-up the workers each visit, rather than facilitating future outings away from her home.

9. Discussion

Our findings add to understanding of how people engage with place when living with dementia. In this section we consider the implications of this learning and set out an argument for altering the approach to community-based dementia support. As a first step we need to address the current framing of dementia that attaches risk to the individual and which creates a logic for containment and even incarceration. We have seen how this can disrupt relationships, silencing the person with dementia while heaping responsibility upon the care partner to keep their loved one safe. Amin (2013) has argued that under conditions of neoliberal governance, an emphasis on risk individualises the management of uncertainty, shifting responsibility for dealing with collective problems from the state to the individual. Consequently, our argument is for creating opportunities for more collectivised responses to getting lost and this includes the potential of reimagining public space.

In order to rethink 'dementia as risk' we need to critically reflect on how the problem of getting lost has been constructed and how this has spurred certain types of response. Getting lost involves unforeseen entanglements of movement, affect and emotion with social, material and immaterial aspects of a person's surroundings. From this perspective, neither dementia nor place appear as continuous in a way that we can isolate, thematise or categorise. We suggest this throws into question

much existing research and community-based support which is oriented to getting lost as a singular category of behaviour. It has been characterised by what Ceci et al. (2020) describe as 'an algorithmic logic of identified problem – targeted intervention' (p.871). Jackson (2013) describes such a response as the imposition of a 'single liberatory strategy' where the 'problem' is pre-determined and a solution is externally derived. She suggests such approaches are always inadequate because they are founded upon the notion of an essentialised and stable identity that 'uniformly persists through continuous time' (p.845).

By contrast, Jackson (2013) argues for a situated response to resolving the challenges that people face, one that takes account of the complexities of their situation. She advocates scrutiny of social and spatial practices, understood as interpretive responses to the layered and dynamic nature of an emergent world. Jackson argues:

Social problems are part of a large, circulating network of power, and what can be done about problems is visible in the responsive practices of people [...] the point is to figure out how to create more fluid, open conditions – or becoming-spaces – within which people can transform themselves (p.846).

Critical of deterministic intervention-style responses to social problems, Jackson's argument is two-fold. First, that we need to re-think approaches to place, relinquishing control over fixed definitions. Second, that we need to revise our understanding of social problems themselves. Rather than static challenges that reside somewhere awaiting resolution, problems are active, produced by (and producing) relations and practices.

With regard to the need to rethink place, De la Llata (2021) has drawn a distinction between an ontology of 'being' and of 'becoming'. He draws upon the activities of social protest movements to critique an 'ontology of being' that seeks to define, fix and regulate (from above) how public space is used and experienced. He argues instead that 'Conceiving spaces of becoming entails acknowledging the limitations of the professional city-maker and recognizing the agency of citizens (even the influence of non-human factors) in urban transformation' (p.18). In a context where people with dementia have long been designed out of public spaces (Blackman et al., 2003), the prospect of supporting their efforts to influence urban transformation could drive policy-making in respect to inclusive neighbourhoods. Indeed, the experience of getting lost with dementia could serve as a litmus test for an emerging dementia-friendly communities (DFC) agenda. Encounters with 'time-spaces of not knowing' suggest a role for DFCs and other place-based dementia initiatives in actively fostering and facilitating debate on the constitution of public space.

With regard to revising our response to getting lost as a social problem, we have seen how the experience itself can be formative in making sense of the relationship with public and outdoor spaces for people with dementia. We found that through getting lost people evolve an array of situated practices to mitigate risk, from careful preparation before leaving home, following particular routes through their neighbourhood, and staying on familiar territory. Such practices help the person face future uncertainty while reducing the sense of threat that it can pose. We need to pay closer attention to what people do in the face of such events (i.e. the performativity of knowledge) and how place itself can be mobilised in aid of recovery and reconstitution.

In looking ahead to a future research agenda, our encounters with participants have highlighted certain methodological limitations. We have come to understand how a narrow focus on dementia as a single category of experience is inadequate for capturing the complexity of people's relationship to their neighbourhood. For instance, Brendan's recasting of getting lost as an act of heroism could be read as signalling how dementia and gender intersect in place. It invites us to consider how getting lost might pose a challenge to certain masculinities and to some men's relationship with public space. Such instances underscore the need to integrate an intersectional lens into methodologies of place. This could involve bringing a situated understanding of dementia into

dialogue with a person's specific social location. Additionally, recent arguments have been made for marrying intersectionality with a life-course approach (Holman and Walker 2021) to better appreciate the cumulative and often lifelong nature of shifting experiences of privilege and disadvantage.

10. Concluding remarks

Schillmeier (2014) argues that the process of 'dementing' poses a threat to an assumed world order (cosmos), it 'disrupts, questions and alters the normalcy of cognitively dominated experiences and related social modes of ordering' (p.48). Foregrounding the process of 'dementing' as a situated event makes different ways of being in the world visible. In so doing, we have shed light on the artifice of 'snapshot' approaches that narrowly focus on the moment of getting lost in order that 'the drive to produce [categorical] homogeneity is preserved' (Ceci et al., 2020, p. 871). Not only does this produce fixed and unvarying notions of the event of getting lost but it amplifies deficit, failing to account for how the person with dementia ultimately overcomes the 'passing fright' of not knowing.

Our research extends understanding of getting lost beyond brain-based explanations, demonstrating that what happens is defined by a relationship to time and place. Neither is this simply a matter of way-finding according to movement from A to B, where design interventions can promise a localised 'fix' with knowable outcomes. We identified a multiplicity of experiences which challenge homogenising notions of the condition tied to essentialising the 'person with dementia' as a subject that uniformly persists in continuous time. Thus, we need to recognise what is at stake in the production of taxonomies of behaviour and how the conceptualisation of supposedly fixed and stable characteristics of dementia foreclose understanding of alternative and more fluid dimensions to social experience. As we have seen, the latter points to an understanding of subjectivity as discontinuous, shifting and iteratively (re)made in time and space (Halberstam 2011; Jackson 2013).

We have also thrown into question ideas of place as a fixed set of conditions adequately resolved through bestowing rights or citizenship status in a way that reifies agency as an attribute of the individual. Instead, we have focused on agency as the effect of a constellation of forces, as illustrated by participants' efforts at re-making their relationship to place in the aftermath of getting lost events. Such reconstitution is not simply a matter of returning to a prior condition but of mobilising place through new knowledge practices, changed affect and the capacity to 'do' getting lost better. Ultimately, such engagement with place offers insights into the possibilities for more inclusive future public spaces and civic cultures.

Ethical approval

Ethical approval was obtained from the NHS Health and Social Care Research Ethics Committee (record reference: 15/IEC08/0007) and the Regional Ethical Review Board in Linköping (the county of Östergötland, Sweden) (record reference. 2013/200-31 and 2014/359-32) as well as relevant institutional approval.

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Declaration of competing interest

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Data availability

A metadata record of the research has been submitted to the UK Data Service.

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