Insights into the motivations, practice, and relationality of dementia care during travel

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Background

- Dementia progressively affects cognitive and social functioning (Connell & Page, 2019).
- Over 55 million people live with dementia globally, projected to double by 2050 (World Health Organization, 2025).
- Most people living with dementia remain in the community, increasing reliance on family and care systems (Akhtar et al., 2017; Tolhurst & Weicht, 2023).
- Informal caregivers – mainly spouses and adult children – provide most care (Bauer, 2019), equivalent to over 40 million full-time workers globally (Wimo et al., 2018).
- Demographic and social shifts are increasing pressure on informal and formal care systems (Wimo et al., 2018).
- Caregiving is demanding and often associated with burden and distress, though experiences vary (Brodaty & Donkin, 2009; Cheng, 2017).
- Care evolves alongside condition progression, reshaping family roles and relational dynamics (Schulz & Martire, 2004; Steadman et al., 2007).

Context

- Tourism environments can intensify cognitive, emotional, and social challenges for people living with dementia (Tomej et al., 2024; Wen et al., 2022).
- Travel capacity varies across the condition; some travel independently in early stages, with increasing reliance on support over time (Bauer, 2019).
- For informal caregivers, travel is inseparable from caregiving responsibilities and can increase burden, including physical strain, fatigue, and distress (Bauer, 2019).
- Despite challenges, travel can foster shared experiences, meaning, and improved quality of life (Hansen, 2022; Innes et al., 2016).
- Tourism becomes a site where caregiving is intensified, negotiated, and made visible (Gillovic et al., 2024).
- Informal caregivers are central to enabling tourism participation but remain under-researched.

Literature review

- Tourism and dementia research has largely prioritised industry perspectives (Connell et al., 2017; Page et al., 2023), with limited focus on informal caregivers' experiences (Innes et al., 2016; Tomej et al., 2024).
- Travel decisions are shaped by prior experiences, perceived needs, and support networks (Edwards et al., 2016; Turner, 2022).
- Caregiving responsibilities limit leisure opportunities (Schulz & Martire, 2004; Wimo et al., 2018); stress, guilt, and safety concerns further restrict participation (Giebel et al., 2025; Peterson et al., 2024).
- Travel choices often favour domestic, familiar, low-risk destinations due to unpredictable care demands (Mullins, 2018; Turner, 2022).
- Dementia can create urgency around travel (e.g., last chance/bucket list trips) (Johnston & Terp, 2015; Tomej et al., 2024), while also intensifying grief, loss, and emotional strain (Mullins, 2018).
- Public interactions may involve stigma and misunderstanding, requiring informal caregivers to manage disclosure and protect dignity (Edwards et al., 2016; Innes et al., 2016).
- Travel offers meaningful connection while simultaneously intensifying caregiving demands, highlighting the need to better understand informal caregivers' lived experiences in tourism contexts.

Study methods

- An interpretive phenomenological approach (van Manen, 1990) was used to explore the subjective experiences of informal caregivers of people living with dementia during travel.
- Data were collected through in-depth, semi-structured interviews (Kvale & Brinkmann, 2009) conducted by phone or online (Irvine, 2011; Salmons, 2014).
- Six informal caregivers (spouses and adult children) who had travelled with a loved one living with dementia participated.
- Interviews explored caregiving roles, relationships, travel experiences, and emotional responses.
- Data were analysed using reflexive thematic analysis to identify shared patterns of meaning (Braun & Clarke, 2019).
- Three key themes emerged: ***'I can only see pain,' 'It's primarily the vigilance,'*** and ***'We've gone from basically equal.'***

Theme 1: *'I can only see pain'*

- Travel was described as *"work"* – physically and emotionally taxing. *"It's not really a holiday; I'll be looking after her"* (Emma). *"But generally, we don't travel. I can only see pain"* (Brian)
- Travel no longer provided rest or respite; caregiving responsibilities continued throughout trips. *"You just torment yourself all the way there and then all the way back"* (Donna).
- As dementia progressed, increasing dependence narrowed travel opportunities and reshaped decision-making. *"She absolutely needs someone with her"* (Tammy).
- Family support, familiar destinations, and established routines were essential in enabling travel and reducing stress. *"To Australia, it's manageable, because we're A, familiar, B, the hospital's the same"* (Bonnie).
- Travel was motivated by a desire to maintain inclusion, connection, and shared memories. *"It's really instances when you're going away as a family and we don't want to exclude him. For our peace of mind, having him there feels like we are including him"* (Elsie).

Theme 2: *'It's primarily the vigilance'*

- Vigilance was ongoing cognitive and emotional labour, involving constant monitoring to prevent wandering, distress, or harm. *"You've got to be with him all the time. You've got to be prepared 24-7, and most people are not prepared for that"* (Bonnie).
- Informal caregivers stayed attentive to mobility, fatigue, safety, and environmental risks in unfamiliar tourism settings. *"You've got to be able to adapt, think ahead, manage risk, all those sorts of things, and also, be very focused on them"* (Tammy).
- It included anticipatory planning and adapting routines to manage risk, emotions, and behaviour. *"She'll say her feelings and she'll say them out loud. She'll complain about everything, and say things like, 'I don't have any bombs'"* (Emma).
- Over time, informal caregivers developed strategies such as route planning, extra time, toilet stops, and spare supplies. *"This has definitely morphed over time, our tact... Just little tips and tricks that we've learned over the years"* (Elsie).
- Caregiving during travel involved sustained mental and emotional effort with little respite. *"It's a lot of mental real estate. There's no break. You are vigilant from the moment they're awake to the moment they're asleep"* (Tammy).

Theme 3: *'We've gone from basically equal'*

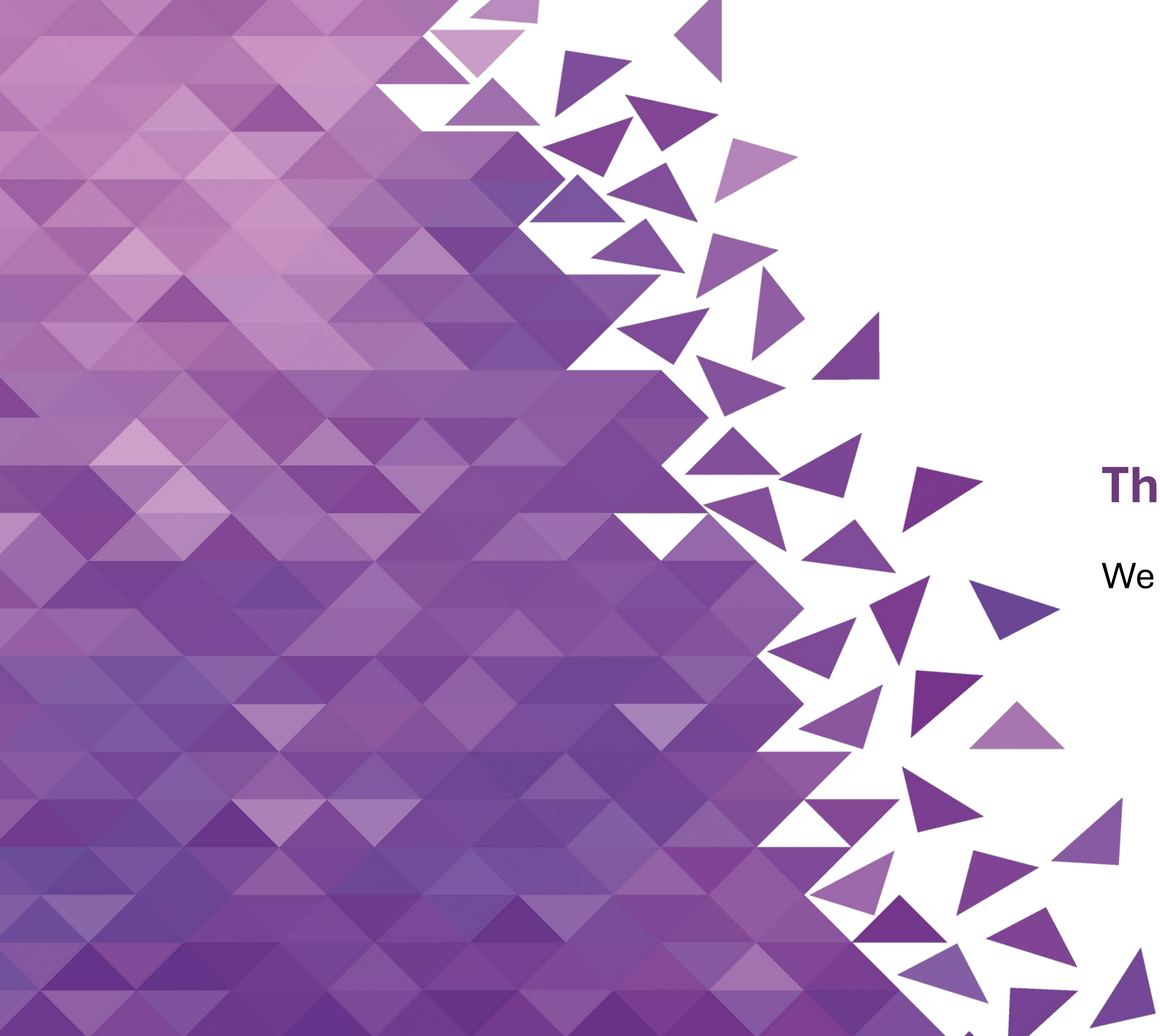
- Travel reflected a shift toward dependence in relational roles. *"We've gone from basically equal to I just take care of everything now. We're still a team; it's me and my shadow. As long as I'm there, he's there; wherever I am, that's his security"* (Bonnie).
- Caregivers assumed full responsibility for planning, decision-making, organisation, supervision, and prompting. *"You do everything, you pack everything, you do all the talking, and they're just coming along. They can't help you at all"* (Emma).
- Some compared it to parenting toddlers, but found dementia caregiving more complex and demanding. *"I feel like I'm parenting a three-year-old adult now. It's really, really difficult"* (Donna).
- Caregivers balanced guidance with preserving autonomy through subtle redirection and avoiding conflict. *"We don't question him, we don't correct him, we don't argue with him"* (Elsie).
- Shifting roles involved loss and emotional strain, reducing reciprocity and connection, increasing loneliness, intensified by prior closeness. *"I would prefer if she had cancer. It may be hard, but at least I had the person. She's still there, but for me, she's not here at all, she's gone. I might get a little bit of her back for a couple of minutes"* (Brian).

Discussion

- Identity and selfhood were sustained through caregiving relationships, with informal caregivers supporting personhood (Kitwood, 1990, 1997) by ensuring inclusion in travel despite cognitive decline.
- Dementia was experienced relationally, with travel supporting identity, meaning, and togetherness (Hellström et al., 2007), even as couplehood became increasingly interdependent and at times strained (Molyneaux et al., 2012; Wadham et al., 2016).
- Vigilance emerged as a continuous form of caregiving during travel, reflecting the ethics of care through protection, attentiveness, and responsiveness to changing needs (Gilligan, 1982; Noddings, 1984).
- As caregiving demands increased, relationship dynamics, equality, and mutuality shifted, reflecting the biographical disruption of dementia and its impact on shared identities and futures (Bury, 1982).
- Findings suggest travel may exist as a ‘possibility’ *“for maintaining a relational identity”* (Karner & Bobbitt-Zeher, 2005, p. 554).

Conclusions and implications

- Tourism participation is shaped by dementia and mediated through relationships, with informal caregivers central.
- Caregiving during travel supports personhood, couplehood, and relational continuity amid biographical disruption.
- Care work is socially significant (Kittay, 2011; Tronto, 1993), reframing accessibility as relational and interdependent rather than purely compensatory (Farkić et al., 2025).
- Tourism can be understood as a moral and relational care space, challenging dominant supply-side approaches (Connell & Page, 2019; Page et al., 2023).
- Greater attention is needed on progressive decline and its effects on relationships, caregiving, and travel experiences.
- Future research should foreground the lived experiences of people living with dementia and their caregivers.
- Inclusion requires recognition of unseen care work alongside improved training, communication, and non-stigmatising practice.



Thank you for listening!

We look forward to your questions.

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