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Family caregivers have become central to community dementia care and yet existing research has primarily focused on caregiver burden, care coordination interventions, as well as the tasks they perform (Layne et al., 2024), providing limited understanding of how caregivers develop the capabilities required to coordinate care. This paper aims to explore how family caregivers develop the capabilities required to coordinate care while supporting people living with dementia in the community.

This study conducted a qualitative analysis of an existing dataset comprising in-depth interviews with 15 family caregivers of people living with dementia in Sri Lanka using Braun and Clarke's (2019) reflexive thematic analysis. The analysis revealed a developmental process through which caregivers progressed from responding to immediate care needs to proactively coordinating increasingly complex care as dementia advanced. Four integrated capabilities underpinned this progression 1) Anticipatory Sense-making: enabling caregivers to recognise and anticipate changing care needs, 2) Adaptive Decision-making: guiding flexible responses to evolving circumstances 3) Care Organisation: organising daily routines, medications, appointments, safety, and everyday care and 4) Care Network Coordination: coordinating family members, healthcare professionals, and community resources.

This study conceptualises this as Adaptive Care Coordination Capability—an evolving capability developed through lived experience that enables family caregivers to sustain continuity of care across changing needs, fragmented health and social care systems. By shifting attention from what family caregivers do to how they develop capabilities to coordinate care, this study offers a new conceptual perspective on family caregiving and provides a foundation for future research, caregiver education, and integrated models of community dementia care.

I will introduce the concept of Adaptive Care Coordination Capability in this presentation by demonstrating how four interrelated capabilities emerged from family caregivers' lived experiences and discussing their implications for community dementia care.

Keywords

Adaptive Care Coordination Capability, Dementia, Family Caregivers, Community Dementia Care, Care Coordination

References

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