

Dementia and Technology

“Not Alone at a Distance”: Co-designing Virtual Palliative Care for Family Caregivers in Rural Ontario

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Purpose Family caregivers in rural Ontario supporting people living with dementia and multiple chronic conditions at the end of life face persistent barriers to timely, coordinated palliative care. Virtual care holds promise for addressing geographic inequities, yet most models are not designed with caregivers and insufficiently reflect the relational, emotional, and practical realities of dementia caregiving [1-2]. The purpose of this study is to co-design an equitable, caregiver-centred virtual palliative care support model tailored to rural contexts. **Method** We employed a co-design methodology guided by the Double Diamond approach, engaging family caregivers, people living with dementia, palliative and primary care clinicians, and community organization representatives across rural Ontario. The study included: (1) discovery and definition phases, using semi-structured interviews to identify caregiver needs, priorities, and system gaps; and (2) development and delivery phases, using co-design workshops to generate virtual care components (e.g., clinical support, care coordination, psychosocial guidance) and barriers and facilitators to implementation. Data analysis and model refinement were informed by the Medical Research Council (MRC) framework for complex interventions, emphasizing feasibility, acceptability, and contextual fit in rural health systems. The co-designed prototype also underwent member-checking by participants. **Results** A total of 18 caregivers and 14 clinicians participated in interviews, 15 participants attended three co-design workshops, and 16 participants completed member-check interviews. Findings highlighted gaps in dementia palliative care, including unclear responsibility for initiating care, difficulty understanding dementia as terminal, long wait times for hospice services, and transportation challenges. The co-designed virtual palliative care model includes five key components. First, AI-assisted information support helps caregivers locate relevant services and understand clinical information in plain language. Second, dementia-specific guidance provides education on disease trajectory, symptom management, and anticipatory planning to support informed decision-making. Third, virtual care delivery through video, chat, or phone reduces geographic and transportation barriers and enables ongoing clinical and psychosocial support. Fourth, peer and caregiver support networks offer emotional support, practical strategies, and shared lived experience. Fifth, the model is contextually tailored to rural settings, integrating local resources and culturally relevant information to ensure feasibility and acceptability. Iterative co-design and feedback from caregivers and clinicians ensure the model is usable, adaptable, and aligned with the MRC framework for complex interventions. **Discussion** These findings suggest that caregiver-centred virtual palliative care can improve access, support decision-making, and enhance equity for families in rural settings. While the co-designed model responds to context-specific gaps in dementia palliative care, its assumptions regarding service availability, digital access, and caregiver roles may not translate directly to other regions or health systems. As such, the model offers transferable principles rather than a universally scalable solution, highlighting the need for local adaptation when embedding virtual palliative care into routine practice.

References

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