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Project: Improving support of substitute decision makers: identification and prioritizing decision-making needs of caregivers of people living with dementia through journey mapping



Background

Through its National Dementia Strategy, the Government of Canada highlighted the priority of improving supports for family/friend caregivers of people living with dementia. Caregivers are crucial in advocating and honoring medical and end-of-life wishes for adults who have lost capacity. This can cause stress, anxiety, guilt and depression lasting for months to years, impacting not just the caregiver but also the person with dementia, their healthcare providers and health resource utilization. Systematic reviews

have identified decision-making barriers and facilitators for caregivers. Barriers include uncertainty about their role and decisions, feeling unsupported by family and healthcare providers, being unclear about wishes of the person experiencing loss of capacity, not recognized as a partner-in-care, and not understanding the dementia disease trajectory.

Objective: Following the Knowledge-To-Action cycle, the objectives are:

1. *Adapt knowledge to local context:* To co-develop journey maps of decision-making experiences from diagnosis to end-of-life of caregivers for people living with dementia in Alberta.
2. *Assess barriers to knowledge use:* To identify where and why existing tools/resources are used/new tools needed in their journeys.
3. *To select, tailor, implement interventions:* To recommend how to implement tools to effectively bridge support gaps in caregivers' journeys.