

## Improving support of substitute decision makers: Journey mapping decision-making needs and use of support tools for caregivers of people living with dementia

Seema King<sup>1</sup>, Gwenn Boryski<sup>2</sup>, Daniel Gaetano<sup>2</sup>, Maria Santana<sup>1,3</sup>, Lorraine Venturato<sup>4</sup>, Jayna Holroyd-Leduc<sup>1,5</sup>, Jessica Simon<sup>1</sup>

<sup>1</sup>Department of Community Health Sciences, Cumming School of Medicine, University of Calgary

<sup>2</sup>Patient Partner, Calgary, Alberta

<sup>3</sup>Department of Pediatrics, University of Calgary, Cumming School of Medicine, University of Calgary

<sup>4</sup>Faculty of Nursing, University of Calgary

<sup>5</sup>Department of Medicine, Cumming School of Medicine, University of Calgary

**Background:** Caregivers are crucial in honoring personal and medical wishes for persons living with dementia (PLwD). Studies have shown caregivers struggle with uncertainty about their role and decisions, feeling unsupported by family and healthcare providers (HCP), feeling unrecognized as partners-in-care, and understanding the dementia disease trajectory. Through a scoping review of current decision-making tools/resources available for caregivers, we found no tool to address all these barriers. Consultation with stakeholders concluded that more information about the caregiver's decision-making journey is needed to guide development and implementation of supports.

**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 PLwD 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.

**Methods:** We will conduct one-on-one interviews with caregivers and focus groups with caregivers and HCP to understand barriers and facilitators to using decision-making tools/resources and to inform caregivers' journey maps of decisions and use of tools/resources. Next, we will host a World Café for stakeholders to select and tailor strategies, guided by the COM-B behavior change wheel, to develop an implementation plan for a toolkit focused on incorporating effective supports across caregivers' decision-making journeys.

**Impact:** (1) Provide foundational knowledge of caregivers' decision-making journey. (2) Describe the current barriers and facilitators to using existing decision-making tools while outlining effective implementation strategies.