

"I never thought I'd have to stand there and make that decision."

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Background

- Family caregivers are key partners on a healthcare team.
- Many caregivers act as substitute decision makers (SDMs) for persons living with dementia
- But they are often unprepared for this role which can cause negative emotional burden.

Aim: To journey map caregivers' decision-making experiences for those living with dementia and the supports they used

Methods

- One-on-one interviews with 25 caregivers in Alberta
- Interviews were transcribed and illustrated
- Identification of decisions and supports were done through theming of written transcripts (researcher) and illustrations (caregiver partners)
- Individual illustrations were shared back with interview participants as a form of member checking

EDI Considerations

- Transdisciplinary team including caregivers as patient partners involved from the start of project
- Purposive sampling of interview participants to hear from those with different:
 - Sociocultural backgrounds
 - Urban/rural residence
 - Gender identities
 - Decision-making stages of dementia disease trajectory
 - Relationships with person living with dementia

Sex & Gender can influence substitute decision-making and was examined with other identity factors.

SUPPORTING CAREGIVERS: A DECISION-MAKING ROAD MAP



These are some of the **MOST COMMON DECISIONS** CAREGIVERS ENCOUNTER, BUT EVERYONE'S JOURNEY IS **UNIQUE**.

Results

- Co-creation of a decision-making road map with caregiver partners
- Caregivers are 'lucky' to happen upon information through word-of-mouth or advocating on their own
- Having legal documents in place, and conversations about goals and wishes help guide and alleviate distress
- Transition to long-term care caused the most negative emotional burden on caregivers

Conclusions

- Caregivers experience haphazard emotional and practical supports for decision-making
- Common decision points provide opportunities for improved supports and tools

Study Impacts

- Helps prepare caregivers for helping their person along the dementia journey
- Fills knowledge & practice gap by identifying common decision points for caregivers & supports for clinicians to offer
- Unique way of integrating arts-based methods (graphic medicine) and qualitative research as an engagement tool in healthcare

Next Steps

- Validate roadmap with caregiver focus groups
- Explore implementation strategies through a World Café with caregivers and healthcare providers

Are you a current/past caregiver of a person living with dementia in Alberta or a clinician/administrator interested in joining the focus groups or learning more about this project?

Please contact: seema.king@ucalgary.ca

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