



# Supported Decision-Making With Persons With Dementia: Challenges, Innovations & Gaps

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# Agenda



**Background on Supported Decision-Making**



**Findings From Scoping Review**

- Literature Review
- Consultations



**Questions, Discussion & Next Steps**

# Background



UN Convention on Rights of Persons with Disabilities: All persons have right to participate in decisions that affect them



Provinces across Canada moving from legislation of substitution to supported decision-making



Policy shift in Quebec requires professionals to prioritize rights/autonomy when questioning capacity

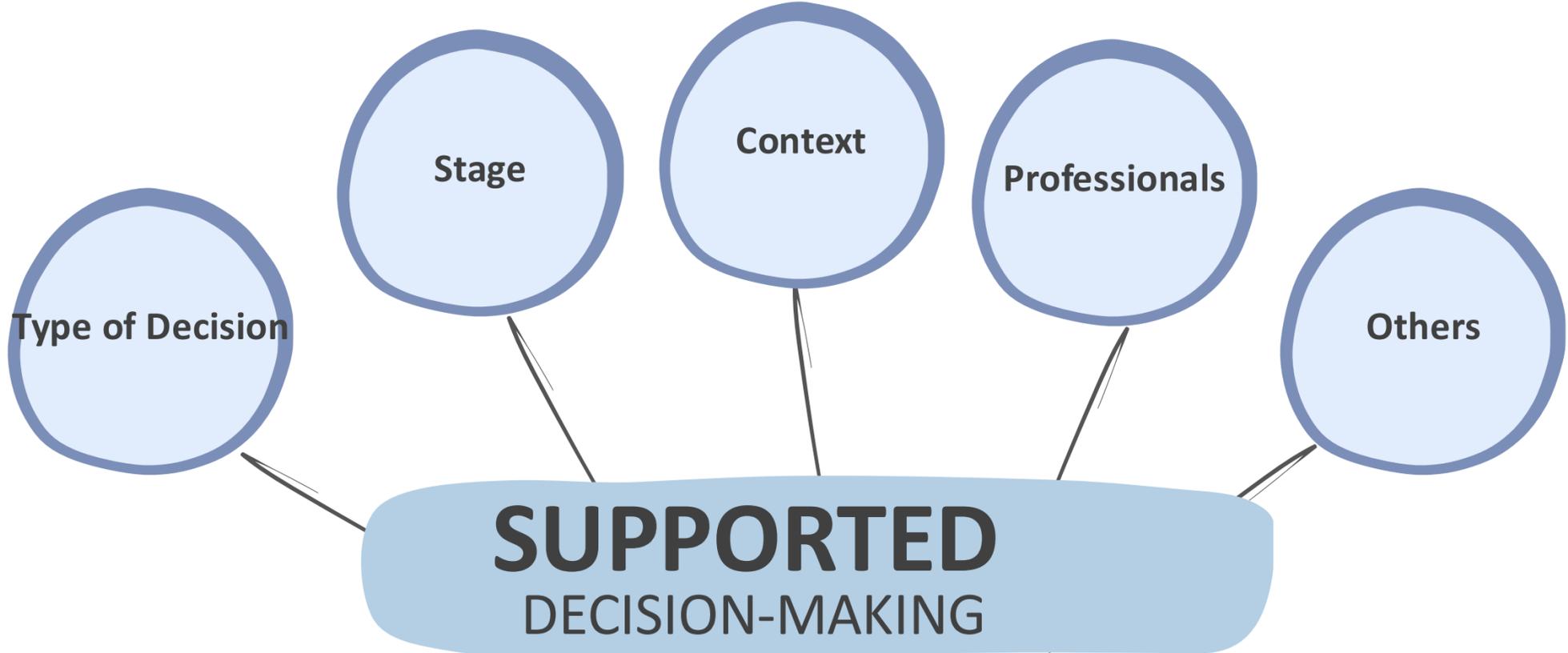
**SUBSTITUTED**

DECISION-MAKING



**SUPPORTED**

DECISION-MAKING



Care Partner



Person with Dementia

# Why Conduct a Scoping Review?



Comprehensive review of  
how to best facilitate  
supported decision-making  
missing



Identifying knowledge gaps  
of importance to persons  
with dementia and their  
care partners could help  
move practice forward

# Two Stage Process



Identify, Review and Summarize Literature

- What types of decisions are described?
- What facilitates or hinders supported decision-making at various stages of dementia?



Consult Advisory Groups of PLWD and Care partners

- How do research findings align with priorities of lived experts?
- What is missing of importance to lived experts?



# Scoping Review Methods: Literature

(N=55)

Broad search terms for  
decision-making

Judgement/choices/prefer  
ences

Broad search terms for  
support

Involvement/  
participation/engagement

Studies had to include  
persons with Dementia

Alone or with care  
partners/professionals





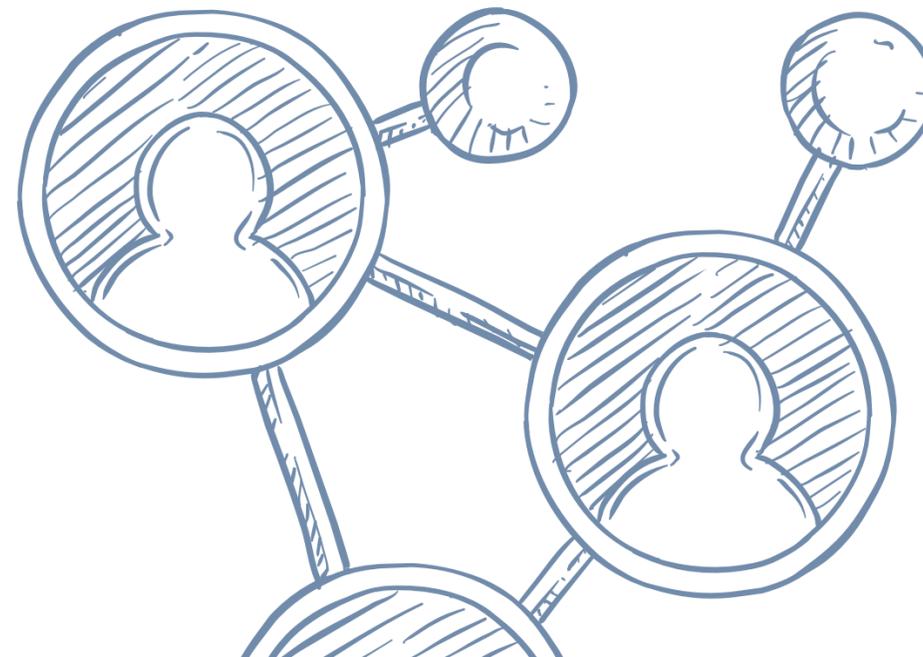
# Scoping Review Methods: Consultations

Advisory Groups:

Persons living with  
Dementia (N=3)  
Care partners (N=9)

Open Exploration

Present and discuss key  
findings





# Findings Literature (N=55)

Voices Presented in Studies	Number (N)	Percentage (%)
Only Persons with Dementia	N= 11	20%
Caregivers & Professionals included	N= 44	80%
Type of Methods	Number (N)	Percentage (%)
Qualitative	N= 39	71%
Quantitative	N= 6	12 %
Mixed	N= 10	17 %

Location	Number (N)	Percentage (%)
Community & Home	N=21	38.2 %
Hospitals	N= 19	34.5%
Residential Homes	N = 12	21.8%
Research Institutions	N= 3	5.5 %



# Findings Literature (N=55)

Stage of Dementia	Number (N)	Percentage (%)
Unreported	N= 47	85%
Total Reported	N= 8	15%
• <i>Early Stages/ Mild</i>	N= 5	< 1 %
• <i>Moderate</i>	N= 3	< 1%



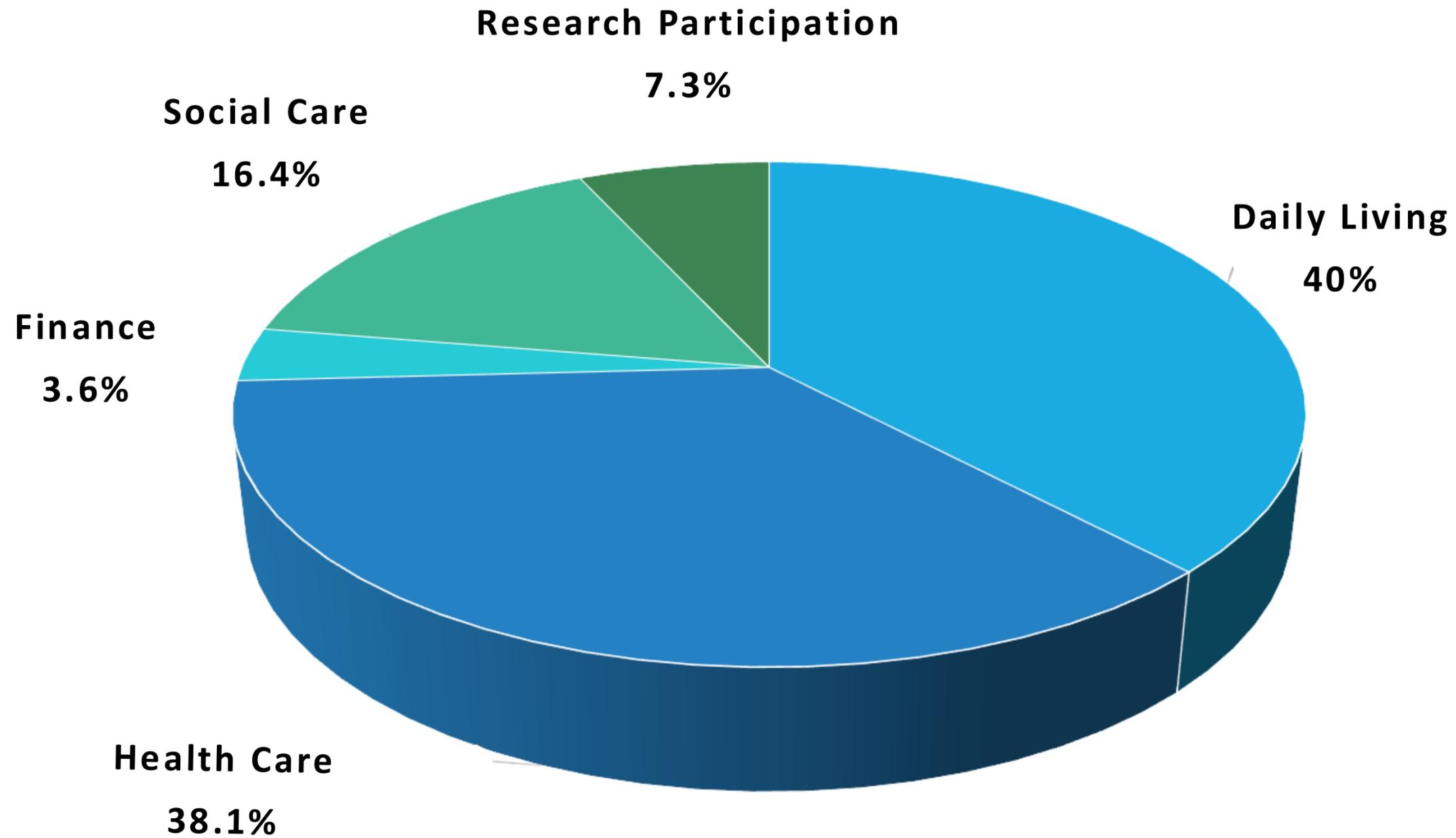
# Findings Literature (N=55)

<b>Gender Distribution (Persons with Dementia)</b>	<b>Percentage (%)</b>
Male	12%
Female	88%
<b>Gender Distribution (Caregivers)</b>	<b>Percentage (%)</b>
Male	41%
Female	59%

<b>Race/Ethnicity of Persons with Dementia &amp; Caregivers</b>	<b>Percentage (%)</b>
White	43%
Black	36%
Hispanic	15%
East Asian	6%



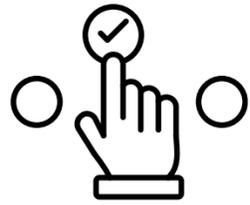
# Findings Literature: Types of Decisions





# Findings Literature: Helpful Factors Persons With Dementia

Communicating preferences



Comfortable with decisions being made on their behalf



Caring non-verbal cues are seen as encouraging



TRUST



FAMILIARITY



EFFECTIVE COMMUNICATION



SUPPORTIVE TOOLS



Places & people increased capacity for involvement



Assistive devices help make daily- living decisions



# Findings Literature: Helpful Factors Caregivers

Trust in person with dementia's capacity



Confidence in professionals guiding them in involvement



Reiterated caring non-verbal cues



Inclusion by professionals supports inclusion by caregivers



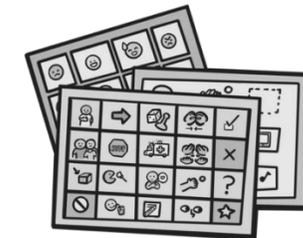
Reiterate that familiar places increase person with dementia's capacity



Regular interaction & knowing person with dementia's preferences



Tools that help person with dementia express themselves





# Findings Literature: Challenges to supported decision-making



LIMITED TIME TO SUPPORT  
PROCESS



VIEW OF BEING RESPONSIBLE TO MAKE  
GOOD DECISIONS



UNCERTAINTY AROUND HOW & WHEN  
TO INVOLVE THEM



# Findings Consultations: PLWDs (N=3)

## Persons Living with Dementia (N = 3)

Gender Identity	Number (N)	Percentage (%)
Men	N= 2	67%
Women	N= 1	33%
Stage of dementia	Number (N)	Percentage (%)
Mild/Moderate	N=3	100%

Living Situation	Number (N)	Percentage (%)
Living alone at home	N= 1	33%
Living with partner at home	N= 2	67%
Relationship to Caregiver	Number (N)	Percentage (%)
Partner (wife)	N= 2	67%
Children	N= 1	33%



# Findings Consultations: Caregivers (N=9)

## Caregivers (N = 9)

Gender Identity	Number (N)	Percentage (%)
Woman	N= 9	100%
Relationship to PLWD	Number (N)	Percentage (%)
Partner (wives)	N=9	100%

PLWD's stage of dementia	Number (N)	Percentage (%)
Moderate / advanced	N= 6	66%
Deceased in advanced stages	N= 3	33%



# Findings Consultations: Care Partners

## Important Decisions:

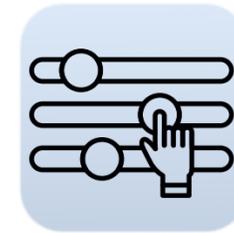
Relocation & M.A.I.D.

Decisions of Daily Living

## Factors Impacting Supported Decision-Making:



Double Exclusion & Systemic Constraints  
(exclusion of self leads to exclusion of other)



Fluctuating Capacity & Constant Adjustment



Doubts of professional competence vs.  
Knowledgeable advice from trusted peers,  
organizations, & professionals



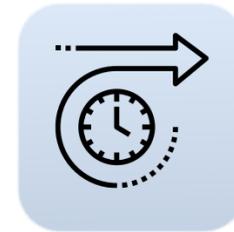
# Findings Consultations: Persons with Dementia

## Important Decisions:

Maintaining self-determination & remaining involved in daily life:

- Preserving value-based living & choices
- Preserving interests & activities
- Preserving sense of self

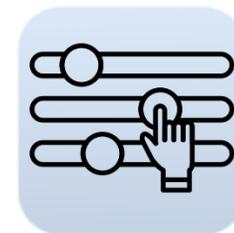
## Factors Impacting Supported Decision-Making:



Complex decisions require space for reflection & common understanding  
(tension vs. collaboration)



Freedom to share & express without immediate concern or interruption  
(hiding vs. trusting)



Adjusting expectations of self **at own pace**  
(dignity vs. devaluation)



# Findings Consultations: Overlapping Themes

## What decisions represent

### Caregivers:

Decisions seen through the lens of responsibility and permanency of outcome.

### Persons with Dementia:

Decisions deeply tied to internal experiences of selfhood and personal meaning.

## Orientation

### Caregivers:

Future-focused, constant anticipation and adaptation to changes.

### Persons with Dementia:

Present- focused, working on retaining sense of self, what's important to them is what is happening now

# Discussion

## Representation in demographics

- *Later stages of dementia* not reflected in literature nor in our group of PLWDs
- Caregivers were all wives in our focus group

## M.A.I.D. & Relocation

- Identified as being of significant importance for caregivers in focus but was not identified in literature
  - Potentially an indication of *caregivers' perceptions and orientations (not identified by PLWDs)*
  - Potentially an indication of *stage of dementia*

## Decisions about daily life

- Emerged as important in both groups with divergence;
  - Caregivers' descriptions of daily life decisions as important *aligned with the literature (described types of activities of daily living, i.e. wheelchairs, dressing)*
  - Persons living with dementia descriptions tended to *tie daily life decision to notions of self-hood (i.e. engaging in activities that nurtured their sense of self)*

## Orientation & what decisions represent

- Less described in the literature but appeared in overlapping themes
- How can these concepts, if at all, shift the way decision-making is experienced, understood, & supported

# Thank you!



## Next Steps:

Three part-interview using photovoice

- Part 1: PWD & Caregiver
- Part 2: Mapping & photos
- Part 3: Open reflective discussion



## Article:

Sussman, T., Ma, X. P., Oyinlola, O., Grenier, A., Cascio, M. A., McCleary, L., Hunter, P. V., Soulières, M., & Zakaria, R. (2024). Supported decision-making with persons with dementia: A scoping review protocol in partnership with lived experts. *BMJ Open*, 14(8). <https://doi.org/10.1136/bmjopen-2024-085954>