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REVIEW ARTICLE

A scoping review of decision-making tools to support substitute decision-makers for adults with impaired capacity

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Abstract

Background: Substitute decision-makers (SDMs) make decisions that honor medical, personal, and end-of-life wishes for older adults who have lost capacity, including those with dementia. However, SDMs often lack support, information, and problem-solving tools required to make decisions and can suffer with negative emotional, relationship, and financial impacts. The need for adaptable supports has been identified in prior meta-analyses. This scoping review identifies evidence-based decision-making resources/tools for SDMs, outlines domains of support, and determines resource/tool effectiveness and/or efficacy.

Methods: The scoping review used the search strategy: Population—SDMs for older adults who have lost decision-making capacity; Concept—supports, resources, tools, and interventions; Context—any context where a decision is made on behalf of an adult (>25 years). Databases included MEDLINE, Embase, CINAHL, PsycINFO, and Abstracts in Social Gerontology and SocIndex. Tools were scored by members on the research team, including patient partners, based on domains of need previously identified in prior meta-analyses.

Results: Two reviewers independently screened 5279 citations. Articles included studies that evaluated a resource/tool that helped a family/friend/caregiver SDMs outside of an ICU setting. 828 articles proceeded onto full-text screening, and 25 articles were included for data extraction. The seventeen tools identified focused on different time points/decisions in the dementia trajectory, and no single tool encompassed all the domains of caregiver decision-making needs.

Conclusion: Existing tools may not comprehensively support caregiver needs. However, combining tools into a toolkit and considering their application

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[Correction added after first online publication on 20 March 2024: The spelling of the second author's first name has been corrected.]

relevant to the caregiver's journey may start to address the gap in current supports.

KEYWORDS

caregivers, decision aids, dementia, substitute decision-making

INTRODUCTION

Over 50 million people in the world are currently living with dementia, and this number is continuing to increase as the world population ages.¹ It is projected that nearly 1.7 million Canadians will be living with dementia by 2050.² Dementia is a progressive disease that impacts an individual's ability to independently manage their activities of daily living. In addition to the physical decline, cognitive decline can include the inability to make decisions for oneself. Many family members and friends often find themselves making medical and personal decisions for people living with dementia (PLwD). This role, either legally appointed or informally assumed, is known as a substitute decision-maker (SDM).³

The responsibility of an SDM is to act on an adult's previously expressed goals and wishes or in their best interests when these goals are not known.^{4,5} SDMs often make decisions for that individual based on previous conversations (if they have had them), written legal documents such as advance directives, their knowledge of the individual and their understanding of the dementia trajectory, and the support they receive from healthcare providers and other family members.^{6–8} However, caregivers are often unprepared for the SDM role, and making decisions for another individual can have negative emotional impacts, such as anxiety, distress, and guilt.^{9–13}

Decision aids have been trialed previously to alleviate this decision-making distress. They have been shown to reduce anxiety, decisional conflict, and uncertainty by increasing knowledge about treatment options and certainty of values relating to specific decisions.^{14,15} They have been shown as useful and acceptable way to provide SDMs with information about dementia, benefits, and risks of treatment options and provide guidance on having effective communication with healthcare providers, social services, and other family members.^{16–18} Previous systematic reviews of decision aids related to substitute decision-making in dementia have focused on the type of decisions made, as well as the mode of intervention (e.g. booklet, webpage),¹⁶ the effectiveness of interventions for shared decision-making,¹⁷ or focused on decision aids at end-of-life.¹⁸ None of these previous reviews evaluated the tools based on previously identified decision-making needs of SDMs through previous systematic reviews and qualitative studies^{7,8,15} nor had SDMs themselves evaluate and compare the tools.

Key points

- Provides a systematic approach to describe the extent to which nine *caregiver-focused* domains are covered in tools used to support caregivers making substitute decisions.
- Includes *caregivers as partners in the scoping review*, with their ratings of the tools.
- Concludes *improvements to tools are needed* to comprehensively support across the domains important to caregivers.

Why does this paper matter?

When substitute decision-makers feel unsupported and are unprepared in making decisions, both they and the person they are making decisions for can be negatively impacted.

The study aims to conduct a scoping review to

- identify self-facilitated tools, resources, supports, or interventions for SDMs of adults with impaired decision-making;
- evaluate the tools on the basis of a range of identified facilitators of substitute decision-making; and
- explore the potential specific use of the tools for SDMs and PLwD.

METHODS

This scoping review was reported following PRISMA-ScR (PRISMA extension for scoping reviews) checklist and was conducted based on the congruent Joanna Briggs Institute (JBI) manual for scoping reviews.^{19,20} It was also registered on Open Science Framework (DOI: [10.17605/OSF.IO/ZXTDG](https://doi.org/10.17605/OSF.IO/ZXTDG)).

Eligibility criteria

The Population–Concept–Context model suggested for scoping reviews by JBI was used.²⁰ Population included

family members and friends making medical or personal decisions for adults (>25 years of age) who have lost capacity to make these decisions for themselves. We excluded resources aimed at SDMs of children, youth, or young adults (<25 years of age) and those where health-care provider or public guardians were making the final decisions. We did not limit the search to include only PLwD because we wanted to include generic resources that still might pertain to decisions SDMs had to make that were not limited to those with dementia, for example moving to continuing care or defining the role of SDMs.

The concept included supports, resources, tools, and interventions that could be used without facilitation from a healthcare provider. The context included any situation where a decision is made on behalf of the adult including decisions within acute care, home, and facility living. Intensive care unit (ICU) settings, where decisions need to be made quickly, were excluded because the context of tools used in crises is not the same compared to many dementia-related decisions that can be arrived at over a relatively longer period of time. Tools were also excluded if they were not tested in some way through think aloud, usability testing, and perceived or measured effectiveness or efficacy. We included all original studies of any design or size and excluded commentary, editorials, and abstracts without manuscripts (e.g., conference abstracts).

Search

A comprehensive search strategy was used to ensure any interventions, tools, and resources aimed at SDMs for decision-making could be captured. We searched three concepts: family AND decision-making AND tools. The search strategy incorporated controlled vocabulary, free-text terms, database operators, and Boolean operators. The searches were limited from 1995 onward, when advance care planning process was defined,²¹ to the date the search was run, which was initially May 17, 2021. The searches were subsequently updated on January 27, 2023. Databases searched included MEDLINE (Ovid), Embase (Ovid), CINAHL (EBSCOhost), APA PsycINFO (Ovid), Abstracts in Social Gerontology (EBSCOhost), and SocIndex (EBSCOhost). The search strategy creation and database selection were done in consultation with a librarian (ZP) who has extensive experience in knowledge synthesis and search strategies. All search strategies are included in Supplementary Table S1. Additionally, we reviewed reference lists of all systematic reviews found by the search strategy.

Study selection

Records were exported from the databases as RIS files and imported into Distiller SR software (Evidence Partners Incorporated, Ottawa, Canada) for deduplication and screening. Two independent reviewers (Initial search: SK, BF and updated search: SK, TJ) conducted first-level screening of titles and abstracts, as well as full-text screening. In both screenings, if either of the two reviewers considered the article met inclusion criteria at the first-level screen, it was automatically moved to the full-text screening stage. In the full-text screening stage, each article was screened by two reviewers, and conflicts were reviewed for inclusion by a third reviewer (JS).

Data extraction

Data were extracted from included studies using a charting table template provided by JBI.²⁰ This included authors, journal, year, country, methods, study design, population, context, aim of study, study inclusion/exclusion criteria, sample, type of cognitive impairment, and data and method of tool evaluation. Characteristics of the tool were also collected such as name, aim, medium, support domain, SDM involvement in development of tool, and evaluation results.

Data evaluation

These tools were scored on their ability to facilitate the needs of SDMs for decision-making, independently by three reviewers. These reviewers included a student researcher (SK) and two patient partners with lived experience of being an SDM for a PLwD (GB, DG).²² DG was the primary caregiver and medical decision-maker for his wife diagnosed with early onset dementia. GB was part of a family unit making medical decisions for her mother diagnosed with vascular dementia. In addition, SK supports her family members who are decision-makers for her grandmother diagnosed with vascular dementia.

Evaluation focused on nine areas of support that have been identified as facilitators to substitute decision-making in previous reviews.^{7,8,15} These facilitators are family support, communication with healthcare providers, knowledge about the dementia trajectory and prognosis, understanding of SDM role, reflecting on previous wishes of the PLwD, providing reassurance in decisions, and being recognized by healthcare providers as a partner-in-care. Tools were also evaluated on whether they supported three main decisions that cause SDMs'

distress: continuing care placement and end-of-life decisions including specifically cardiopulmonary resuscitation (CPR) and feeding routes.^{8,15}

RESULTS

Information about articles

A total of 5279 records were identified through database searches after removal of duplicates (Figure 1). 25 articles met inclusion criteria and were selected. The included studies were published between 2003 and 2022. Most studies ($n = 11$) took place in the USA^{23–33} followed by Canada ($N = 4$),^{34–37} Japan ($N = 2$),^{38,39} Australia,⁴⁰ Germany,⁴¹ Ireland,⁴² United Kingdom,⁴³ and Switzerland⁴⁴ ($N = 1$ for each country). Three studies were conducted by a research group based out of the Netherlands, but all involved a single tool that was translated into a few languages and used

internationally.^{45–47} Most studies ($n = 12$) used mixed methods.^{25–30,34,35,37,40,41,45}

Information on tools

We identified 14 tools from the 25 included full-text articles (summarized in Table 1). Some articles evaluated the same tool but in different contexts, and some were translations of an original tool for use in different countries.^{41,42,45–47} Most tools ($n = 9$) are in the form of booklets, pamphlets, or brochures. All tools were self-facilitated, but six were also studied in conjunction with facilitation such as a HCP consultation, or a workshop.³³ Most of the tools provide educational information, with some addressing some of the psychosocial aspects of caregiving. Tools also covered a variety of decisions including driving cessation ($n = 2$), medical decisions ($n = 8$), general care decisions ($n = 2$), and facility or service decisions ($n = 2$).

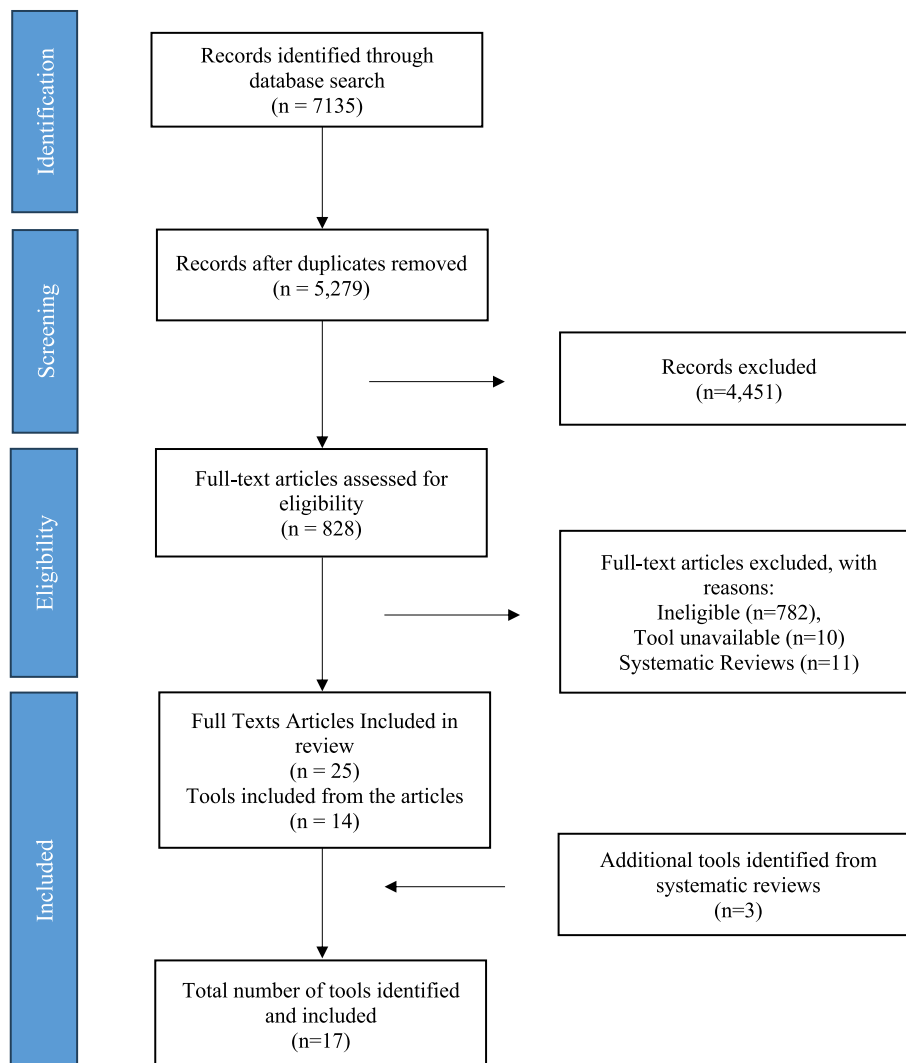


FIGURE 1 PRISMA flow diagram of search results.

TABLE 1 Tools identified in review that are aimed at supporting substitute decision-makers.

Tool	Decisions	Medium	Support domain	Facilitation	Evaluation domains	Articles
Fact box decision support tool	Antibiotics for pneumonia and artificial hydration	Brochure	Education	Self	Knowledge and decisional conflict	Loizeau, Theill, Cohen, Eicher, Mitchell, Meier, McDowell, Martin, and Riese, ⁴⁴ Switzerland
Safety in Dementia	Driving cessation and firearm safety	Website	Education	Self	Acceptability	Polzer, Nearing, Knoepke, Matlock, Azrael, Siry, Meador, and Betz, ²³ USA
Go to the Hospital or Stay Here?	Transfers to hospital	Pamphlet	Education	Combination of self and with interventionist	Knowledge, preparedness, and decisional conflict	Tappen Ruth, Worch Sarah, Newman David, and Hain, ²⁶ USA
The Palliative Approach for Advanced Dementia in LTC	General care decisions and trajectory information	Pamphlet	Education	Self	Acceptability and comfort with EOL discussions	Sussman, Kaasalainen, Bui, Akhtar-Danesh, Mintzberg, and Strachan, ³⁵ Canada
Planning for Long-term Care	Selecting a LTC facility	Website	Education	Self	Usability and feasibility	Hoffman, Bateman, Ganoe, Punjasthitkul, Das, Hoffman, Houston, Peirce, Dreyer, Tang, Bennett, and Bartels, ²⁵ USA
A Family Caregiver Decision Guide	General caregiver decisions	Workbook and interactive website	Education	Self or used with navigator	Acceptability and usefulness	Robinson, Bortoff, Pesut, and Zerr, ³⁴ Canada
At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving	Driving cessation	Psychoeducational	Education, psychosocial	Group Education session	Self-efficacy, coping, and stages of change	Stern, D'Ambrosio, Mohyde, Carruth, Tracton-Bishop, Hunter, Daneshvar, and Coughlin, ³³ USA
The Gold Book (Guiding Options for Living with Dementia)	Respite services	Booklet	Education	Self	Carer burden	Stirling, Leggett, Lloyd, Scott, Blizzard, Quinn, and Robinson, ⁴⁰ Australia
Understanding Stroke	Information on stroke, prognosis	Web-based tool	Education	Self	Developed through card sorting and usability testing	Chen, Arslanian-Engoren, Newhouse, Egleston, Sahgal, Yande, Fagerlin, and Zahuranec, ²⁷ USA
Comfort Care at the End of Life for Person's with Alzheimer's disease and other degenerative Diseases of the Brain—A Guide for Caregivers	Palliative care and end-of-life treatment options	Booklet	Education	Self but some studies used in conjunction with healthcare provider facilitation	Acceptability, usefulness, and decisional conflict.	Riedl, Bertok, Hartmann, Fischer, Rossmeyer, Dinkel, Ortner, and Diehl-Schmid, ⁴¹ Germany Brazil, Carter, Cardwell, Clarke, Hudson, Froggatt,

(Continues)

TABLE 1 (Continued)

Tool	Decisions	Medium	Support domain	Facilitation	Evaluation domains	Articles
Making choices: Feeding Options for Patients with Dementia	Feeding options	Booklet; Audio booklet	Education	Self	Communication, knowledge, and decisional conflict	McLaughlin, Passmore, and Kernohan, ⁴² <i>Ireland</i> Van der Steen, Arcand, Toscani, de Graas, Finetti, Beaulieu, Brazil, Nakanishi, Nakashima, Knol, and Hertogh ⁴⁵ ; van der Steen, Hertogh, de Graas, Nakanishi, Toscani, and Arcand ⁴⁶ ; Bavelaar, McCann, Cornally, Hartigan, Kaasalainen, Vankova, Di Giulio, Volicer, Arcand, van der Steen, Brazil, and the mySupport study, ⁴⁷ <i>Canada, Netherlands, Italy</i> <i>Mitchell, Tetroe and O'Connor</i> , ³⁶ <i>Canada</i> Hanson, Carey, Caprio, Lee, Ersek, Garrett, Jackman, Gilliam, Wessel, and Mitchell, ³¹ <i>USA</i> Snyder, Caprio, Wessel, Lin, and Hanson, ³⁷ <i>USA</i> Ersek, Sefcik, Lin, Lee, Gilliam, and Hanson, ³² <i>USA</i> <i>Kuraoka and Nakayama</i> , ³⁸ <i>Japan</i> Kuraoka and Nakayama, ³⁹ <i>Japan</i>
Caring for someone with dementia through to the end of life: A decision aid	Changes in care, Eating and drinking, Everyday wellbeing for PLWD, healthcare tests and medication	Booklet	Education, psychosocial	Self	Feasibility and acceptability	Davies, Aker, Vickerstaff, Sampson, and Rait, ⁴³ <i>United Kingdom</i>

TABLE 1 (Continued)

Tool	Decisions	Medium	Support domain	Facilitation	Evaluation domains	Articles
Advanced Dementia—A Guide for Families	Information on dementia, palliative care and hospice, feeding, infections & goals of care	Booklet	Education, Psychosocial	Used in consultation with geriatrician and palliative care nurse	Feedback from HCP, chaplain, geriatrician, bioethicist and three proxies	Catic, Berg, Moran, Knopp, Givens, Kiely, Quinlan, and Mitchell, ²⁴ USA
A Decision Aid about Goals of Care for Patients with Dementia	Medical decisions about goals of care	Video	Education	Self, followed by structured discussion with LTC care team	Feasibility, relevance, quality of communication, and concordance between SDM and HCP on goals of care and palliative care domains in care plan	Einterz, Gilliam, Chang Lin, McBride, and Hanson, ²⁸ USA Hanson, Zimmerman, Song, Lin, Rosemond, Carey, and Mitchell, ²⁹ USA Hanson, Song, Zimmerman, Gilliam, Rosemond, Chisholm, and Lin, ³⁰ USA

Facilitators addressed by tools

Table 2 shows the final consensus between the three evaluators (SK, DG, and GB) regarding which facilitators each of the tools addressed. In addition to the 14 tools from the review, we also included three online tools in the evaluation. These were chosen from a systematic review that was identified through the review, and the online tools were evaluated by the authors using content analysis.⁴⁹

Enables communication with healthcare providers

Over half of the tools (10/17) were rated as supporting active communication, through their provision of lists of questions or concerns that the SDM should be asking a healthcare provider. This category created the most discussion from reviewers, with some uncertainty about whether two of the tools (#3 and #4, Table 2) would sufficiently encourage SDMs to engage in discussions with healthcare providers.

Elicits family support

Many tools (11/17) were found to encourage the caregiver to seek support rather than making decisions in isolation. Specifically, tools suggested ways for the SDM to seek support from family or others when decision-making.

Role of SDMs and reflecting on the PLWD wishes

Most tools (12/17) commented on reflecting on the PLWD's previous wishes, while only half (9/17) explained the role of an SDM.

Reducing uncertainty of decisions and providing reassurance in the decisions

Evaluators felt that most tools (12/17) reduced uncertainty by listing the advantages and disadvantages of future decisions. A stand-alone tool's ability to provide reassurance was the most subjective category, causing the most variation in opinions between the three evaluators. After discussion, evaluators agreed that half of the tools (9/17) were able to provide some reassurance through scenarios of each decision made, or by providing

TABLE 2 Evaluation of tools scored on ability to meet decision-making needs of substitute decision-makers.

Tools	Areas of support							Addresses key decisions of:			
	Enables communication with HCP	Elicits family support	Reflect on previous wishes	Reduces uncertainty in decisions	Provides reassurance	Helps SDM to be recognized	Explains trajectory	Placement	EOL	CPR	nutrition
1. Fact box decision support tool											
2. Safety in dementia	✓			Potentially			✓				
3. Go to the hospital or stay here?	Potentially		✓	✓							
4. The palliative approach for advanced dementia in LTC	Potentially		✓				✓				
5. Planning for long-term care	✓		✓					✓			
6. Pathway fact sheet ^a	✓		✓					✓			
7. A family caregiver decision guide	✓		✓	✓							
8. At the crossroads: Dementia & driving	✓		✓	✓							
9. The gold book (guiding options for living with dementia)	✓		✓	✓							
10. Understanding stroke (p 10–12)	✓		✓	✓							
11. Factsheet for SDM ^a	✓		✓	✓					✓		Not specifically but generally
12. Making medical decisions for another person ^a	✓		✓	✓					✓		✓
13. Comfort care at the end of life: A guide for caregivers	✓		✓	✓					✓		✓
14. Making choices: feeding options	✓		✓	✓					✓		✓
15. Caring for someone with dementia through to the end of life: A decision aid	✓		✓	✓					✓		✓
16. Advanced dementia: A guide for families	✓		✓	✓					✓		✓
17. A decision aid about goals of care for patients with dementia	✓		✓	✓					✓		✓

Abbreviations: CPR, cardiopulmonary resuscitation; EOL, end-of-life; HCP, healthcare provider; SDM, substitute decision-maker.

^aAdded from Sellars, Chung, Nolte, Tong, Pond, Fetherstonhaugh, McInerney, Sinclair, and Detering.⁴⁸

some education or prognosis information on treatment options.

The SDM being recognized as part of the healthcare team

Only 5/17 tools expressed the importance of the SDM role or stated that the caregiver is part of the healthcare team.

Providing education on the dementia trajectory or prognosis

Almost half (8/17) the tools explained the dementia trajectory or outlined that it is a terminal illness. However, it was noted that only nine tools were specifically focused on SDMs of PLwD.

Addressing some of the major decision points that caregivers identified as the most difficult

Among the many difficult decisions that caregivers face, studies identified four particularly distressful decisions: placement, end-of-life decisions, specifically CPR, and end-of-life nutrition options.^{8,15} Only 10/17 tools covered decisions related to any one of these topics.

No single tool covered all of the facilitators. Two tools, *Advanced Dementia—A Guide for Families* and *A Decision Aid about Goals of Care for Patients with Dementia*, included the most facilitators. Both these tools covered all the facilitators to support needs, except for the decision of placement.

DISCUSSION

This scoping review of tools to support SDMs of adults with impaired decision-making identified 17 self-facilitated tools that had undergone user testing. Only six met more than half of the known facilitators to substitute decision-making. These six tools were largely focused on end-of-life (EOL) issues such as CPR and nutrition modalities, which have been highlighted by Su, Yuki, and Hirayama⁸ and Lord, Livingston, and Cooper¹⁵ as some of the more distressing decisions for SDMs to make. However, the major decision point of deciding whether a PLwD can remain at home or needs to move to a more supported care environment was not addressed by these tools, nor was it addressed by most of the 17 tools

identified. Out of the four tools that addressed transitioning to continuing care, only two were specific to dementia.

Similar to the review conducted by Davies, Schiowitz, Rait, Vickerstaff, and Sampson,¹⁶ we found that, overall, the tools targeted different areas of the SDM's journey in decision-making. This variation makes sense, as previous studies have described the SDM role as a journey, progressing from shared decision-making with the PLwD to substitute decision-making as dementia progresses.^{11,50} Depending on the individual's capacity, caregivers may need to make a wide variety of decisions for the PLwD, such as when to stop driving, where they live, medical decisions about transfer to hospital, which medications to take, or if life-sustaining treatments will be attempted.

Of all facilitators to decision-making, most tools suggested the SDM reflect on previous wishes. This is not surprising as law in many jurisdictions requires that SDMs consider what decision the PLwD would have chosen for themselves.⁵¹ Many studies have shown advance care planning (ACP), defined as “the process of understanding and sharing values, wishes and preferences of medical treatments if one loses their capacity to make decisions for themselves,”⁵² can lessen the emotional impacts on SDMs. These conversations can also improve correlation between patient wishes the medical treatments they receive and decrease stress among SDMs.^{6,9,12,53} Studies have expressed the importance of having these conversations early with PLwD, soon after diagnosis, allowing patients to be able to express their wishes more fully. Additionally, these early conversations aid family members who will be tasked as SDMs to prepare for this role by providing better understanding of their person's values, preferences, and wishes.⁶ Reviews of SDM experiences of PLwD have shown that knowing the patient's wishes before having to make these decisions increases confidence in decision-making and decreases distress and anxiety.^{8,9,50} However, studies have also shown that only about one quarter of adults with serious illness have spoken with their SDM about their values, leaving the majority of SDMs thrust into the role of substitute decision-making without preparation.¹² Hence, there is a need for SDM decision aids that can be used whether or not ACP has occurred.

It should be noted that decision aids on their own, similar to other passive resources, are not intended or able to support all SDM needs. Although all identified tools were self-facilitated, six of them were also used in conjunction with a workshop or with a HCP. Throughout the literature, SDMs emphasize the need for communication from HCP, the need to be recognized as partners-in-care and having support from families so as not to feel alone in decision-making.^{7,8} A trusting relationship with

healthcare staff has been identified to ease some of the negative emotional burden that SDMs face when making decisions.¹⁰ Although tools do not seek to replace the in-person communication, they can facilitate active communication with healthcare providers through question prompts.^{29,35} They might also help encourage the SDM to seek out in-person support when this has not been offered, or help the SDM reflect on discussed topics, reducing their decision-making distress.^{26,32,36,42–44}

This is true for family support as well. SDMs often feel isolated in their decision-making^{8,11} and have noted family support eases some of the emotional burden. Although tools cannot substitute for such support, encouraging the SDM to elicit family support when making these decisions could be helpful. Few tools reminded SDMs to speak to family or provided resources or other supports to help with these discussions. Although navigating familial conflict was another challenge for SDMs, this was only briefly mentioned in two of the tools.

Given that no single tool meets the decision-making needs of SDMs, further development is required. This could include iterative co-redesign of existing tools to address their gaps. In addition, healthcare providers should be mindful in identifying specific decision-making needs of each SDM and use combinations of tools or develop toolkits to address these. Our team is exploring the decision-making journey from diagnosis to death and the tools currently utilized by caregivers of PLwD to create a supportive roadmap for use by both caregivers and healthcare providers.⁵⁴

A strength of this study is the integration of SDM partners into the data evaluation portion of this scoping review. These decision aids were made for SDMs; however, not all papers disclosed if and how SDMs were part of the creation of the decision aid. In this study, having SDMs evaluate the tools allowed us to provide that knowledge-user perspective to these tools. The importance of partnering with knowledge users is a pillar of both integrated knowledge translation and patient-oriented research.^{22,55} Integration of patient partners has been emphasized throughout the research process, but few studies have found effective ways to involve patients in the knowledge synthesis phases of research.^{56,57}

As this was a scoping review, we did not assess the methodological quality of the included studies. Evaluation of the primary studies has been done in previous systematic reviews,^{16–18} and thus, our goal was to evaluate the tools in their ability to meet the needs of SDMs. A limitation was the subjectivity in evaluating the extent to which a tool meets the needs of SDMs, and there were only three evaluators making this determination. Although there was consensus in most categories about whether a tool could support SDMs in facilitating

particular aspects of decision-making, there were difference of opinions in some categories such as providing reassurance in decisions.

CONCLUSION

This study identified 17 tools that can support SDMs in making decisions for PLwD. When evaluated against facilitators for substitute decision-making identified in previous studies, only two tools included most items. Overall, tools were aimed at different parts of the dementia journey, suggesting a need for dynamic, iterative preparation and SDM support that includes a toolkit of decision support resources. The next steps of this inquiry include exploring how SDMs use or could use decision aids within the greater context of their SDM journey and in relation to other peer and healthcare provider supports.

AUTHOR CONTRIBUTIONS

Jayna Holroyd-Leduc, Jessica Simon, Seema King, Maria J. Santana, and Lorraine Venturato contributed to study concept and design; Seema King, Brooklynn Fernandes, and Zahra Premji helped in acquisition of data; Seema King, Gwenn Boryski, Daniel Gaetano, Brooklynn Fernandes, and Timothy S. Jayme helped in the analysis; Seema King, Gwenn Boryski, Daniel Gaetano, Jessica Simon, and Jayna Holroyd-Leduc contributed to the interpretation of data; Seema King prepared the manuscript; and Brooklynn Fernandes, Timothy S. Jayme, Gwenn Boryski, Daniel Gaetano, Zahra Premji, Lorraine Venturato, Maria J. Santana, Jessica Simon, and Jayna Holroyd-Leduc reviewed the manuscript.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflicts.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Data S1. PRISMA-ScR-Fillable-Checklist.

Supplementary Table S1. Initial and updated search strategies for each database.

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