

Shared decision making in mild cognitive impairment

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Abstract

Shared decision making (SDM) occurs when patients and clinicians consider patients' values and preferences while discussing medical evidence to inform healthcare decisions. SDM enables patients with mild cognitive impairment (MCI) to express values and preferences when making current healthcare decisions and presents a unique opportunity to inform future decision making in the case of further cognitive decline. However, clinicians often fail to facilitate SDM with patients with MCI. This review describes research pertaining to value solicitation, weighing of the medical evidence, and medical decision making for individuals with MCI, explores the role of caregivers, identifies barriers to and facilitators of SDM in MCI, and suggests strategies to optimize SDM for persons with MCI in neurology clinical practice. Further research is needed to identify more strategies for decision support for individuals affected by cognitive impairment.



Shared decision making (SDM) describes a partnership where patients and clinicians make healthcare decisions by considering patients' values and preferences alongside the best medical evidence.¹ Incorporating SDM in clinical care increases patient understanding, satisfaction, and trust² and has short-term and long-term benefits for individuals, teams, organizations, and healthcare systems.³ Despite increasing emphasis on SDM as an essential component of high-quality healthcare,¹ only 47% of U.S. adults report that clinicians consider their goals and concerns.⁴ This is particularly true for older adults, where healthcare decision making frequently fails to focus on individual needs and preferences.⁵

Mild cognitive impairment (MCI) is common in older populations and present worldwide, suggesting that neurologists are frequently encountering this population in clinical practice.⁶ Although clinicians recognize the importance of including persons with MCI (pwMCI) and their family members in medical decision making, they often fail to do so.⁷ SDM with pwMCI offers unique challenges given the presence of cognitive decline, but also a unique window for clinicians to establish the goals and preferences while those values can be reliably and competently voiced. This is particularly important given the risk of progression to dementia for pwMCI.⁶ In this commentary, we review research pertaining to SDM for pwMCI and suggest ways to optimize SDM for pwMCI in neurology clinical practice.

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Shared decision making in MCI

After identifying that a medical decision needs to be made, SDM includes 3 steps: (1) identifying patient values and preferences, (2) discussing and weighing medical evidence, and (3) reaching a decision (figure). Each step has unique considerations for the pwMCI and carepartners/relatives.

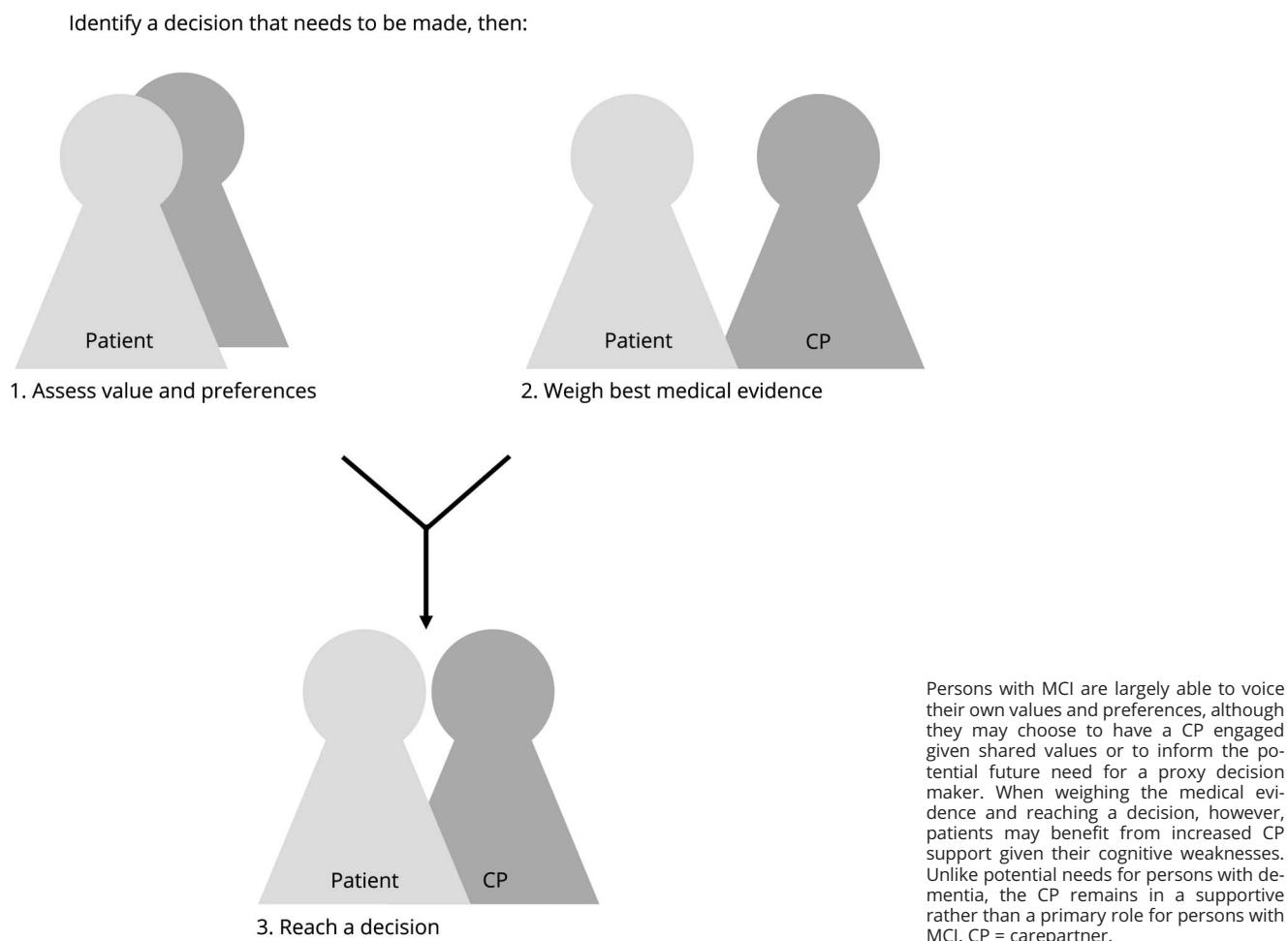
1. *Identifying patient values and preferences.* Values and preferences emanate, at least in part, from cultural and lifelong learning. Thus, the ability to express values and preferences relies on remote memory, which is preserved in MCI. Evidence shows that pwMCI have the capacity to articulate preferences.⁸ Although research regarding preferences of pwMCI is increasing, it tends to focus on the values or perception of values of families/caregivers,^{9,10} suggesting a continuing need for focusing on pwMCI.
2. *Discussion and weighing medical information:* In this step, clinicians present information about the decision and potential benefits and risks of available options.¹¹ Weighing medical information in decision making involves the abilities to retain, process, and integrate information. This

requires recent memory skills, which are commonly compromised in MCI. Studies of capacity with pwMCI show that these individuals can have difficulties understanding treatment situations and options and appreciating the consequences of treatment decisions.¹²⁻¹⁴ Helping patients compensate for recent memory deficits may help mitigate some cognitive limitations. It is critical that clinicians incorporate pwMCI in this step since they remain able to understand and appreciate treatment decisions and options—just not as well as their healthy counterparts.¹⁴

3. *Decision making.* In the final step, patients reach a decision with caregiver/family and clinician support. Although capacity studies suggest that the ability of pwMCI to voice rational reasons for treatment choice can be compromised,^{9,13,15,16} pwMCI still make “reasonable” choices¹⁶ and have no difficulties in their ability to express a choice.^{13,16}

Most healthcare decision making literature on pwMCI focuses on amnesic MCI. Although difficulties in decision making in MCI commonly relate to impaired memory and executive function,¹⁶ experiences vary based on underlying

Figure Conceptual model of shared decision making with persons with mild cognitive impairment (MCI)



Clinicians are responsible for engaging patients at the level of their abilities, which change over time and vary based on MCI severity and subtype.

pathology. Nonamnesic MCI affects attention, insight, executive function, language and/or visual perceptual abilities, with associated implications. Determinants of medical decision making are not solely due to cognitive impairment but also include character traits, values, preferences, experiences, and amyloid burden.¹⁵

Role of carepartners/family

Autonomy in healthcare decision making is highly valued by pwMCI, with most wanting relatives to have limited control of medical decisions.⁹ Because pwMCI are able to independently express values and preferences,^{8,9,16} carepartners have a modest role in expressing values informing decision making (figure), similar to the supportive carepartner role for patients without cognitive impairment.¹⁷

There are benefits in having carepartners present during medical visits. Carepartners can learn the pwMCI’s values and preferences, informing their future potential proxy role should MCI progress to dementia.⁸ This is particularly important as patient and caregiver/relative preferences can differ.⁸⁻¹⁰ Preferences may vary depending on relationship (e.g., spouse, child, or friend) or cognitive impairment severity (e.g., mild vs moderate).¹⁰ Individual characteristics, demographics, culture, and the decision making context also influence how patients and relatives interact when decision making. Carepartners present during medical encounters

have a larger role in assisting patients in processing information and weighing medical evidence and choices¹⁷ than the step of value expression (figure).

Barriers and facilitators

Barriers to successful SDM include physician-, patient- and carepartner-level barriers and other considerations (table 1).¹⁸⁻²¹ Caregiver/family involvement can be a barrier to successful SDM if families use their own preferences to make decisions, answer for the patient, or defer decisions to staff when patients are in living facilities.²⁰ Facilitators are often the converse of described barriers. In addition to clinician motivation, a sense of partnership, and inclusion of others (e.g., family) for decision support, numerous practical strategies can support successful SDM with pwMCI (table 2).¹⁸⁻²¹

Decision aids (DAs) are another SDM facilitator. DAs are tools that guide patients, carepartners, and clinicians through SDM by using value solicitation exercises and outlining medical evidence for different options. DAs increase patient knowledge and accuracy of risk perceptions, lower decisional conflict, reduce patient passivity in decision making, increase congruency between values and choices, and improve patient-clinician communication.²² DAs have particular promise for improving decision making in MCI given their potential to address cognitive weaknesses. For patients with MCI who may retain information only briefly, the combination of sufficient time and decision support can improve SDM.^{19,20,23} In Alzheimer disease, use of a one-page memory and organizational aid to supplement an informed consent form resulted in improved understanding on a measure of capacity.²³ Whereas a search of online DA libraries revealed no current DAs targeting pwMCI, pwMCI face common decisions that could benefit from structured support including whether to pursue biomarker testing, take medications or supplements aiming to improve cognition, participate in clinical trials, and stop driving.

Table 1 Examples of barriers to SDM

Physician-level barriers	Patient- and CP-level barriers	Other barriers
Attitude (e.g., lack of agreement with SDM, no expectation of benefit)	Attitude (e.g., expectation of a passive role)	Patient-physician relationship
Lack of familiarity, experience with SDM	Perceived unacceptability of asking questions	Lacking continuity of care
Physician knowledge of evidence	Ability to understand health-related information (health literacy), education	Environment (noise, lack of privacy)
Poor communication skills	Patients undervaluing expertise	Time
Insufficient explanations	Physical limitations (e.g., poor hearing)	Lack of resources, reimbursement
Use of medical terminology	Cognitive limitations	Embarrassing or sensitive topics
Overspecialization	Differences between patients (individual preferences, abilities)	Not having a family member present

Abbreviation: CP = carepartner; SDM = shared decision making.

Table 2 Strategies to improve SDM in MCI

Category	Facilitators of SDM for persons with MCI
Overall approach	Assess the presence of MCI vs dementia
	Clarify patient preferences regarding SDM, CP involvement
	Establish continuity of care
	Hold discussions in a quiet environment without distractions
	Allow adequate time
	Engage CPs with patient's permission
Value solicitation	Re-evaluate over time
	Identify short-term and long-term values and preferences
Presentation of medical evidence, decision making	Encourage patients to discuss values with identified healthcare surrogate decision makers/proxies
	Identify cognitive weaknesses and provide additional support
	Use print tools (e.g., guideline patient summaries, DAs)
	Employ teach-back methods
	Engage CPs with patient's permission

Abbreviations: CP = carepartner; DA = decision aid; MCI = mild cognitive impairment; SDM = shared decision making.

Implications for practice

These considerations provide strategies for successful SDM with pwMCI (table 2). Clinicians are responsible for engaging patients at the level of their abilities, which change over time and vary based on MCI severity and subtype. Although challenging, clinicians must be alert for signs of progression to more severe cognitive impairment, suggesting that patients are no longer able to safely make decisions unaided, while not limiting pwMCI participation prematurely. The role of SDM in dementia is currently largely unexplored.

Clinicians must clarify patients' wishes regarding carepartner involvement. Some patients appreciate or require extra help, but others may not need or want family involvement. Determining the degree of family involvement is complex given variability in cognitive impairment, insight, and degree of autonomy desired. Some older adults want to receive information and actively participate in decision making¹⁸; others take a passive role and want clinicians to make final decisions.^{9,18} This does not obviate the need for SDM, but requires clinicians to choose the option most in line with patients' stated values and goals.¹⁷ Patient preferences do not trump clinician responsibilities for ensuring safety (e.g., recommendations for driving cessation), but outside of legal and safety concerns, PwMCI may reasonably make decisions that differ from family or clinician preferences.

Determining the degree of family involvement is complex given variability in cognitive impairment, insight, and degree of autonomy desired.

Environmental factors are particularly important in the context of cognitive impairment, where having a quiet, distraction-free room is helpful.²⁰ Allowing adequate time and avoiding rushing patients are also important. Carepartners can be important facilitators of SDM and should be encouraged, when appropriate, to assist with current decision making and prepare for the proxy role. Clinicians must identify patients' preferences and cognitive weaknesses and adapt communication strategies and the amount of information and how it is presented.¹⁸ A person with attention deficits benefits from a quiet room and undivided attention. A person with amnesic concerns may benefit from written prompts and avoiding delays in decision making. Executive impairments may require simplification of decisions or carepartner engagement. Visual tools can help communicate information or treatment options when receptive language impairments are present. Print tools (e.g., patient/family guideline summaries, formal DAs) provide patient-friendly summaries of relevant data, address the barrier of medical jargon by using plain language, and serve as a memory cue to help patients process and retain information without having to mentally hold the information.²³ Teach-back methods—cycles of asking patients to explain what they learned and clarifying misunderstandings until understanding is confirmed—can improve self-efficacy and adherence in individuals with chronic diseases²⁴ and may also have utility for enhancing understanding in MCI.

Conclusion

SDM allows pwMCI to voice their values and preferences, engage in decision making affecting current healthcare decisions, and informs future decision making, a particularly important opportunity given the risk of progression to dementia. Research suggests, however, that clinicians often fail to engage pwMCI in SDM despite recognizing its importance. Clinicians need to identify and use mechanisms to support pwMCI in SDM given the presence of cognitive weaknesses affecting decision making. Research is needed to explore successful engagement of pwMCI in SDM, the effect of decision support in MCI, and matching decision support mechanisms to specific cognitive weaknesses in MCI.

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Appendix 1 Author contributions

Name	Location	Role	Contribution
Andrea M. Mejia, MA	University of Florida, Gainesville	Author	Conceptualization of the study, interpretation of the data, and drafting of the manuscript
Glenn E. Smith, PhD, ABPP-cn	University of Florida, Gainesville	Author	Conceptualization of the study and revision of the manuscript for intellectual content
Meredith Wicklund, MD	University of Florida, Gainesville	Author	Revision of the manuscript for intellectual content
Melissa J. Armstrong, MD, MSc	University of Florida, Gainesville	Author	Conceptualization of the study, interpretation of the data, and revision of the manuscript for intellectual content

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