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Lived Experience Panel



Perspectives on Evaluating and Measuring Goal-Concordant Care for People Living with Dementia

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Plain Language Summary

This report describes the major lessons learned from a series of discussions between people living with dementia, care partners, researchers, healthcare providers, and other community members about ways to improve the quality of healthcare for people living with dementia. The main topic of these discussions was ‘goal-concordant care’ which means ensuring that healthcare treatments and decisions are in line with what matters most to patients and families. Panel members were asked to discuss their experiences talking about goals with their healthcare providers and how thinking about their goals could help with making healthcare decisions. Some key takeaway points are:

1. Decision-making for people living with dementia is more often driven by needs and priorities, than by healthcare “goals.”
2. Decision-making for people living with dementia involves many people, which is not often reflected in research.
3. It can be difficult for people living with dementia and care partners to feel actively involved in healthcare decision-making.

Further study is needed to identify strategies to ensure that people living with dementia and care partners are actively involved in decision-making and in identifying the best ways to measure whether the needs and priorities of people living with dementia and care partners are being met.



Executive Summary

In September 2023, the [IMPACT Patient and Caregiver Relevant Outcomes Core](#) led a series of 3 discussions with IMPACT's [Lived Experience Panel](#). The meetings were held via Zoom and facilitated by IMPACT's [Engaging Partners Team](#). The topic of focus was goal-concordant care, an important outcome for researchers seeking to understand and improve the quality of healthcare for people living with dementia. Goal-concordant care is defined as the alignment of healthcare decisions and treatments with patients' known goals and values, particularly during advanced or end-stage illnesses. The goal of this collaboration was to understand how goal-concordant care can best be measured to reflect the values and preferences of people living with dementia and care partners. Across the 3 discussions, members of the Lived Experience Panel were asked to reflect on their understanding of goal-concordant care, their experiences discussing goals with healthcare providers, and how goals and preferences could be used to aid in healthcare decision-making. Conversations were structured around a series of open-ended questions and several real-life scenarios which centered around shared decision-making. Throughout all sessions, the panel discussed the opportunities and limitations of goal-concordant care as an evaluation measure for research.

Key Takeaways and Reflections

Lived Experience Panel members emphasized the following points during our sessions:

Address needs and priorities before addressing goals

Goals-based language (e.g., goal-concordant care) does not reflect the experiences and priorities of people living with dementia and care partners. Relatedly, the focus of goal-concordant care on medical decision-making may exclude other equally important decisions.

Meaningful outcomes of goal-concordant care should evaluate whether care decisions address the needs and priorities of people living with dementia and care partners.

Research assessment of goals is complex

Goal-concordant healthcare decision-making is influenced by many complex and competing priorities and involves input from multiple parties including family members, care partners, and providers. **Measurement of goal-concordant care for research needs to reflect the influence of multiple inputs on healthcare decision-making.**

New measures and/or processes are needed to assess engagement

Measuring goal-concordant care from the perspective of the healthcare system or payor is limiting and does not reflect meaningful engagement in decision-making. Relatedly, healthcare utilization as an outcome measure is subject to systemic barriers and structural inequities, and it is not known how these factors may influence receipt of goal-concordant care. **There is a need for outcome assessment that captures engagement or inclusion in healthcare decision-making and future research to identify systems-level barriers and their influence on receipt of goal-concordant care.**



About the NIA IMPACT Collaboratory

The [National Institute on Aging \(NIA\) IMbedded Pragmatic Alzheimer's disease \(AD\) and AD-Related Dementias \(AD/ADRD\) Clinical Trials \(IMPACT\) Collaboratory](#) (U54AG063546) was established in 2019 to build the nation's capacity to conduct [embedded pragmatic clinical trials](#) (ePCTs) of non-pharmacological interventions within health care systems to improve the care of people living with Alzheimer's disease and Alzheimer's disease-Related Dementias (AD/ADRD). The IMPACT Collaboratory does this through a coordinated effort between IMPACT's leadership and topic-focused [Cores and Teams](#) to:

- Develop and disseminate best practice research methods;
- Support the design and conduct of embedded pragmatic clinical trials, including pilot studies;
- Build investigator capacity through training and knowledge generation;
- Catalyze collaboration among community partners, healthcare providers, and investigators; and
- Ensure research includes culturally tailored interventions and people from diverse and under-represented backgrounds.

These Cores and Teams are made up of experts in their fields who work together under the direction of IMPACT leadership to develop and share best practice research methods, support the design and conduct of embedded pragmatic clinical trials, and provide guidance to IMPACT members and researchers.

About the Alzheimer's Association[®]

The [Alzheimer's Association](#) is the leading voluntary health organization in care, support, and research for Alzheimer's disease. Its mission is to lead the way to end Alzheimer's and all other dementias by accelerating global research, driving risk reduction, and maximizing quality care and support. Its vision is a world without Alzheimer's and all other dementias. [®]

About the Lived Experience Panel

The [Lived Experience Panel](#) reflects a coordinated effort between the National Institute on Aging (NIA) IMPACT Collaboratory and the Alzheimer's Association. Established in 2021, the Lived Experience Panel is a group of 9-12 people living with cognitive symptoms or caring for people living with dementia. Panel members help inform research priorities and challenges by sharing their thoughts and experiences with researchers from IMPACT's Cores and Teams in ongoing panel meetings. The Lived Experience Panel meetings cover different topics that may span more than one meeting. Generally, each topic area is introduced with a simple presentation by IMPACT research team members, followed by a discussion with panel members to capture their thoughts and feedback on the topic presented.



The diverse community of members participate in panel activities for one to two years. New panel members are added as previous panel members complete their participation period. Members are selected through an outreach and application review process. The current panel is made up of ten people reflecting various perspectives, including:

- Person living with dementia (PLWD): Individuals with a documented diagnosis of early-stage Alzheimer's, Mild Cognitive Impairment (MCI), or other early-stage dementia.
- Care partner: Care partners/caregivers representing their own experience caring for a person living with dementia.
- Proxy: Caregivers representing the perspective of one or more people living with dementia with middle or late-stage dementia or who are deceased.

The types of dementia represented by panel members include Alzheimer's (7 members), Vascular dementia (1), and Mild cognitive impairment (2). Some panelists represented more than one type of dementia. The panel included people with the following characteristics and identities: Female (7), Male (3), Asian-American (1), Black or African American (3), White (4), and Latina (2).

About the Engaging Partners Team

The IMPACT [Engaging Partners Team](#) focuses on engaging community partners—including patients, care partners, clinicians, administrators, healthcare system leadership, community-based organizations, and public health entities—in all aspects of developing and conducting embedded pragmatic clinical trials among people living with dementia and their care partners. Team members create and share guidance and training materials about working with community partners during embedded pragmatic clinical trials, and support IMPACT researchers in developing strategies for meaningful collaboration with community partners throughout the research lifecycle.

About the Patient and Caregiver Relevant Outcomes Core

The IMPACT [Patient and Caregiver Relevant Outcomes Core](#) focuses on developing and supporting the use of outcomes pertaining to people living with dementia and their care partners in the design and conduct of embedded pragmatic clinical trials.



The Lived Experience Panel Report

Summary reports are written by the IMPACT Core or Team that facilitates the meetings for each topic area and reviewed by members of the Lived Experience Panel before being published and shared with the public. All reports are available on the [IMPACT website](#).

This report summarizes insights and perspectives from the IMPACT Collaboratory [Lived Experience Panel](#) on the topic of measuring and evaluating goal-concordant care in dementia. Reflections were collected through a series of conversations between the Lived Experience Panel, the [Patient and Caregiver Relevant Outcomes Core](#), and the [Engaging Partners Team](#) during Fall 2023.

Overview

Goal-concordant care consists of treatments and services that help individuals reach desired goals while avoiding or reducing treatments that go against these goals.¹ As individuals living with dementia progress to more advanced stages of the disease, the balance of potential benefits and harms of treatments may change.¹⁻³ Thus, achieving goal-concordant care is an outcome of an ongoing and effective process of shared decision-making between healthcare providers, the person living with dementia, and care partners. Prioritizing goal-concordant care assumes that when people living with dementia and their care partners are heard and understood by healthcare providers, the treatment choices are more aligned with their values and goals. Measurement of goal-concordant care can be challenging. **Patient- and care partner-expressed goals, values, and preferences are infrequently documented and often lack detail sufficient to determine whether treatments provided were actually goal-concordant.**^{4,5}

In its current form, goal-concordant care is mostly measured from the perspective of providers, systems, and payors, with a focus on single endpoints of an episode of care (e.g., hospice enrollment, place of death, hospitalizations). This limited view overlooks important personal values not directly related to treatments and healthcare delivery like living independently, driving, and accessing support services. People living with Alzheimer's disease and related dementias and their care partners expressed that they are making decisions based on their values constantly over the course of the dementia, and goal-concordance for treatments at the end of life is not the most salient, nor is it the sole measure of person-centered care considering the long course of dementia. To date, assessments and evaluations of goal-concordant care for research have lacked acknowledgement of the person living with dementia or care partner perspective.

In this series of meetings, members of the Lived Experience Panel were asked to discuss their understanding of healthcare goals, the role of their personal priorities and values in medical decision-making, and ways in which their priorities, values, and goals should be recorded and



used for decision-making and for research. The methods for obtaining perspectives and insights from the panel are described below as well as key themes that emerged from the sessions.

Methods

The goal of this collaboration was to learn about opportunities and limitations of evaluating goal-concordant care for people living with dementia. The Patient and Caregiver Relevant Outcomes Core created a series of broad discussion prompts to elicit panel members' perceptions and understanding of goal-concordant care and developed several decision-making scenarios accompanied by discussion prompts to explore panel members' priorities, values, and decision-making processes.

A series of three 90-minute video calls were held in September of 2023 with members of IMPACT's Lived Experience Panel, Engaging Partners Team, Patient and Caregiver Relevant Outcomes Core, and members of the Alzheimer's Association. Each discussion was facilitated by a member of the Patient and Caregiver Relevant Outcomes Core, with introductions and closing facilitated by the Engaging Partners Team. Agendas, pre-reading materials, and discussion questions were shared with panel members prior to each meeting.

Meeting 1 | September 8, 2023

One of the session facilitators introduced the definition of goal-concordant care and described how it is measured for research. Then, panelists were asked to share their own experiences with goal goal-concordant care. Specifically, the discussion was centered around the following prompts:

1. Do you think about having goals for your care (or about other people having goals for their care)? What types of goals do you (or others) have related to care?
2. Can you share a time when you thought the care you (or someone else) received matched your/their goals?
3. Can you share a time when you thought the care you (or someone else) received did not match your/their goals?
4. In what ways is "goal-concordant care" important?

Throughout the discussion, the facilitators took notes on the discussion, asked clarifying questions, and used follow-up prompts to ensure that panelists' thoughts and perspectives were being interpreted and recorded accurately. Several members of the panel also used the chat feature in zoom to contribute shorter comments.



Meeting 2 | September 13, 2023

One of the session facilitators provided a high-level summary of the main themes and ideas that were discussed in the prior meeting. Panelists were asked to provide any additional ideas that were not represented in the summary. One of the facilitators then led the group through a discussion of two real-life situations that required choices. The first scenario was a situation in which a family member may no longer be able to drive safely, due to worsening dementia symptoms. The implied choice was whether there should be an intervention to stop the family member from driving. The second scenario centered around the occurrence of a fall that may have been caused by adverse effects of a medication. The implied choice was to continue or stop the medication and whether the potential long-term benefits of the medication outweighed the potential short-term risks.

For each situation, panelists were also asked to discuss the following:

1. What do you think about while making the decision?
2. How do you make the decision? Do you talk with others (e.g., family, friends, doctors)? How do you weigh the benefits, harms, and uncertainty?
3. How do you know you made the 'right' decision?

The facilitators took notes, asked clarifying questions, and provided follow-up prompts throughout the discussion.

Meeting 3 | September 28, 2023

The meeting began with a recap of the prior two meetings. The facilitator re-emphasized why the team was interested in understanding and measuring goal-concordant care and why it might be relevant to people living with dementia, care partners, and families. Just as was done in Meeting 2, the discussion was centered around two new real-life situations and how goals, priorities, and values might be used for medical decision-making.

In the first scenario, the panel was presented with two treatment options following a serious health event: 1) a surgical intervention with no guarantee of a cure and a long recovery period or 2) non-curative outpatient medical management of symptoms. Panelists were asked:

1. What priorities and values would you have in mind while deciding about whether to have surgery or not?
2. What would be helpful to identify your (or your family member's) priorities and values?

In the second scenario, the panel was asked to imagine they had experienced a critical health event that required emergency care but left them unconscious or unable to make their own healthcare decisions. Panel members were then presented with an example tool to elicit and record their preferences for medical interventions (e.g., POLST (Physician Orders for Life-



Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) form). Panelists were first asked to discuss the utility of the tools for documenting preferences for treatment as well as their limitations. They were then asked to answer the following questions in relation to this scenario:

1. Who should know your priorities and values?
2. How should your priorities and values be recorded?
3. How would you want that information to be used?

Consistent with previous meetings, the facilitators took notes, asked clarifying questions and provided prompts throughout the discussion. The meeting concluded with the group facilitators thanking the panel for their participation in the series of discussions and indicating that a follow-up meeting would be scheduled to review the summary report prepared by the Patient and Caregiver Relevant Outcomes Core.

Themes

All meetings were recorded and transcribed using Zoom Video Communications software. Patient and Caregiver Relevant Outcomes Core members reviewed all recordings, transcripts, and notes after each session and again at the conclusion of the final session. Key themes that emerged from all three discussions were reviewed and refined. A summary of each theme is presented below, along with a summary table with example quotes and sub-themes.

Theme 1: “Goals”-based language (e.g., goal-concordant care) does not reflect the experience and priorities of people living with dementia and care partners.

One of the themes that emerged early in our discussions and carried throughout subsequent sessions was a consistent disconnect between panelists’ lived experiences with decision-making throughout the course of dementia and the concept of goal-concordant care, as it is currently defined and measured. Relatedly, the goals-based language used by healthcare professionals and researchers was difficult for panelists to connect with their own healthcare experiences in which individual decisions are infrequently discussed in the context of broad, overarching goals (Sub-theme 1.1). For example, several panelists indicated that goals were never addressed during discussions with healthcare providers. Most panelists had a negative view of the term ‘goal-concordant care’ feeling that it may oversimplify or dehumanize the complicated and emotional process of decision-making for individuals and care partners (Sub-theme 1.2), which includes more than just goals for treatment (Sub-theme 1.3). Finally, panelists provided insight into their personal goals, preferences, and values (Sub-theme 1.4). Many of these themes focused on preserving function and maximizing comfort and quality of life.



Theme 1. Goals-based language (e.g., goal-concordant care) does not reflect the experience and priorities of people living with dementia and care partners.	
Sub-Theme 1.1: Lack of Discussion of Goals with Providers	<p><i>"I can't remember a single provider in my life, asking me what my goals were for treatment. [...] I don't have a clue about how to talk about goals with my wife's caregivers now, and with all the people that are now involved in her life. I don't. Not a single person has asked me."</i></p> <p><i>"Physicians or medical providers did not use the term goals. But my mother, without using that term, did in fact have goals."</i></p>
Sub-Theme 1.2: Language Used to Discuss 'Goals' and 'Goal-Concordant Care'	<p><i>"I use words like values and goals. [...] I will tell you when I use these words like, it's our family's goals or values."</i></p> <p><i>"It seems so sterile, and so cut and dried, and there was nothing cut and dried about what we went through, and that's I'm having a little hard time putting it together."</i></p>
Sub-Theme 1.3: Considerations beyond treatment goals in decision-making for people living with dementia and care partners	<p><i>"What? What? What can you expect to happen? What, what would it look like if we do these things?"</i></p> <p><i>"But is it gonna make any difference? And I think that again, is the big question in my mind for priorities and values... the main thing that helps with that."</i></p>
Sub-Theme 1.4: Example Goals of Care (as expressed by panel members)	<p><i>"Our goal was really to do as much as possible that we used to."</i></p> <p><i>"I think that would be kind of one of my top priorities, and my value would be the quality of life given either one of the decisions."</i></p> <p><i>"...my value is to protect Dad's comfort...for him not to go to the hospital, but a priority is also my relationship with my sister."</i></p> <p><i>"I want relief from this."</i></p> <p><i>"...it's a matter of keeping me as comfortable as possible."</i></p>

Theme 2: Goal-concordant healthcare decision-making is influenced by many complex and competing parties and involves multiple inputs from family members, care partners, and providers.

Another theme that was consistent throughout each session was how decision-making is complicated by multiple inputs and perspectives at both the systems level and the personal



level. Several panelists discussed how conflicting viewpoints among family members may contribute to emotional stress both on the part of the decision-maker and the person receiving care (Sub-theme 2.1). Panelists also indicated that decisions may be highly influenced by individuals other than a person's designated healthcare decision-maker ("hidden decision makers"), which may include vocal or opinionated family members. The complexity of navigating multiple healthcare providers was also discussed. Panel members indicated that such outside influences need to be identified and considered to fully characterize the decision-making process (Sub-theme 2.2).

Theme 2. Goal-concordant healthcare decision-making is influenced by many complex and competing parties and involves multiple inputs from family members, care partners, and providers.	
Sub-Theme 2.1: Conflicting Family Perspectives	<p><i>"...and then you throw in my daughters and other family members or friends. It gets complicated."</i></p> <p><i>"...one of you'll have to choose to accept the other's decision if you're in disagreement and that's tough being the proxy."</i></p> <p><i>"but a priority is also my relationship with my sister. [...] it would be very difficult for him if his 2 daughters had different opinions about what he should do [...]"</i></p>
Sub-Theme 2.2: Social and Systems Complexities in Decision-making	<p><i>"...in many families there are hidden decision-makers. Alright, they may not be obvious, you know, in their decision-making power. But they are, in fact, influencing the person that the provider ultimately may hear from."</i></p> <p><i>"That's how sometimes hidden decision-makers enter into the equation because, you know, there might be a need for interpretation, just an interpretation of what the providers are saying."</i></p> <p><i>"I think there's some outside forces on when we're trying to make those decisions that kind of complicate it again, not knowing just exactly what they are."</i></p> <p><i>"But sometimes you have to manage that whole family constellation to come up with a decision. [...] There are lots of providers involved, and I'm not sure who can manage that."</i></p> <p><i>"She had so many different medical providers that it was very difficult for us to meet her goals."</i></p>



Theme 3: *Measuring goal-concordant care from the perspective of the healthcare system or payor is limiting and does not reflect meaningful engagement in decision-making.*

Finally, panelists discussed how the healthcare system itself creates challenges for making healthcare decisions that are aligned with their priorities and values. Panelists engaged in a powerful discussion around their perceptions of how empowered or engaged they feel in their interactions with the healthcare system. Multiple panelists expressed frustration and disappointment with their sense of powerlessness and lack of opportunity to ensure that they or their loved ones receive the care that is best aligned with their needs and values (Sub-theme 3.1). Relatedly, panelists discussed how the healthcare system itself imposes structural inequities and barriers that prevent people from receiving healthcare that aligns with priorities and values (Sub-theme 3.2). For example, one panelist discussed how differences in income likely contribute to disparities in the choices available and the types of decisions that need to be made by patients and care partners. Despite the challenges discussed, some panelists did have experiences with providers who were skilled in helping navigate goal-concordant decision-making. And others were able to identify concrete needs (e.g., social services, family caregiver support) along with resources (e.g., decision-aids) that would be helpful for engaging in decision-making to achieve goal-concordant care. (Sub-theme 3.3) These may include culturally- and contextually relevant resources and decision aids to assist caregivers with decision-making for dementia care, as well as access to social services and family caregiver support.

Theme 3. Measuring goal-concordant care from the perspective of the healthcare system or payor is limiting and does not reflect meaningful engagement in decision-making.	
Sub-Theme 3.1: Perceived Empowerment (i.e., a person’s sense of being able to advocate for the person living with dementia and to get information)	<p><i>“My wife happens to be a very good advocate, and she asked a lot of the hard questions. I’m afraid to ask the hard questions in the doctor’s office... I’m more passive when it comes to the doctor’s office, and not asking the questions or being as good of an advocate for my wife as she is for me.”</i></p> <p><i>“I used to joke with colleagues that the place where I feel most powerless in life is the doctor’s office. [...] I realized that I have been trained to be passive in a doctor’s office. And in no other aspect of my life have I ever felt that way. [...] I’m not a good advocate for myself in a doctor’s office and I am a worse advocate for my wife.”</i></p> <p><i>“Sometimes I’m not competent. I don’t know what the right thing is. I don’t have the information, the knowledge, or whatever but other times it’s just flat out irrational.”</i></p>



<p>Sub-Theme 3.2: Challenges in Making Goal-concordant Healthcare Decisions</p>	<p><i>“But what if we don’t have the resources the infrastructure that is going to support that, particularly for folks that may be undocumented, for folks that are not eligible, based on criteria around socioeconomic status. [...]there has to be conversation about what’s possible.”</i></p> <p><i>“... religion and culture and education level and ability to speak the same language as your medical provider, and read at the same level...”</i></p> <p><i>“...our life changed. I just felt totally at a loss of what to do. And there was no one that I knew that I could really talk to about that. And none of the professionals that were in our lives helped out in that regard.”</i></p>
<p>Sub-Theme 3.3: Opportunities for Making Goal-concordant Healthcare Decisions</p>	<p><i>“...it was really hard, but so helpful to have an expert, compassionate medical provider to speak to us as 2 daughters, but with like different understandings of what the outcome could be, and I appreciated it greatly as the final decision maker, so that my sister wouldn't feel as though I was taking away an opportunity from Dad”</i></p> <p><i>“We could have my daughters and I and my wife could have really used some sort of a tool or a process, when we were making or considering these decisions about memory care, and so on. If we could have gone through a discussion of what are our priorities and values.”</i></p> <p><i>“I wish that I had had at the time was more support for this decision from our clinical team. [...] But looking back, I really could have used that clinical expert advice.”</i></p>

Discussion and Recommendations

Evaluation of goal-concordant care for people living with dementia presents a conceptual problem (i.e., person-centered relevance) as well as measurement problem (i.e., clinical significance).

The panel noted an overall lack of discussion of goals and lack of information for care partners about the availability of treatments and the expected outcomes of their decisions to pursue or forgo care. Thus, the idea of measuring goal-concordant care, based on apparent “goals” and the care received, was perceived as out-of-touch with reality and not representative of the nuanced decisions and treatment pathways that care partners face. Decision-making was discussed as a recurring component of daily, ongoing care for people living with dementia and



their care partners. An overarching theme in these discussions was that treatment decision-making is a highly complex process in that it can include: an urgent need to address an issue (i.e., “putting out fires”), multiple family member perspectives, as well as coordination of care and gathering of information across multiple providers.

One reason for the discordance between goals-based language and care partners’ experiences may be that most research on goal-concordant care focuses on the systems/payor perspectives emphasizing healthcare activities (i.e., health services utilization and setting) over personal experiences. Additionally, much of the existing research and interest in goal-concordant care is focused on decision-making near the end of life.⁴ In the context of end-of-life care, evaluation of goal-concordant care is relatively straightforward – i.e., evaluating whether treatments that are burdensome or those for which the risks do not outweigh the potential benefits are avoided. Our discussions with the Lived Experience Panel were not specifically focused on end-stage disease or end of life care, but also addressed early- or mid-stage disease. Nonetheless, the application of goal-concordant care to people living with dementia may be an oversimplification of the longitudinal, progressive nature of the disease.⁶ Current methods for measuring goal-concordant care focus largely on all-cause end-point outcomes (e.g., avoidance of hospitalizations, place of death), rather than stepwise decision-making that is often tied to immediate priorities that fluctuate and evolve throughout disease progression.

Despite the related challenges, achieving goal-concordant care remains an important aspiration for our health care system. It aims to ensure that people living with dementia and their families receive health care that aligns with their values. This likely requires some adaptation from end-of-life care and translation to the context of dementia. Below we have summarized key challenges and recommendations for future work to address the current limitations of measuring and evaluating goal-concordant care in people living with dementia.

Challenges and Recommendations for Measurement and Evaluation of Goal-Concordant Care

Challenge #1: The term “goal-concordant care” is primarily a research term that is seldom used in real-world discussions with healthcare providers in the context of dementia care. People living with dementia and care partners do not often think of healthcare in terms of “goals, but rather as priorities or “putting out fires.” Additionally, the narrow focus of goal-concordance on healthcare decision-making ignores other relevant decisions that are driven by the same priorities and values.

Recommendation #1: Brief patient or care partner reported outcome measures may be more effective in capturing the extent to which care is goal-concordant if patient- and care partner-facing assessments and terminology focus on unmet needs, priorities, or values. Further study is needed to develop a conceptual framework that operationalizes goal-concordant care for people living with dementia and care partners distinct from its inception in palliative and hospice care.



Challenge #2: Current methods for evaluating goal-concordant care in dementia care lack the nuance to capture the complex, real-time decisions that are influenced by multiple decision-makers.

Recommendation #2: Efforts to measure goal-concordant care may benefit from an evaluation of the entire experience/course of dementia rather than focusing on single treatment decisions or endpoints (e.g., time to hospice enrollment, place of death). Relatedly, measures should seek to reflect the influence of multiple decision-makers on decision-making for people living with dementia.

Challenge #3: Healthcare system barriers and inequities can make it hard for people with dementia and their care partners to engage in decisions that align care with their goals. Dealing with many healthcare providers and a lack of relevant resources makes it hard for people with dementia to actively engage with the healthcare system. Financial inequities also limit options for some people living with dementia and their care partners.

Recommendation #3: There is a need for outcome assessment that captures engagement or inclusion in healthcare decision-making. Examples may include: 1) whether needs (as expressed by patients and care partners) were met, or opportunities were missed, based on care received; 2) whether care partners felt heard and understood during the decision-making process for healthcare treatments. There is also a need for research about how systems-level barriers and inequities affect the receipt of goal-concordant care.

Conclusion

Goal-concordant care, as it is currently measured, may not reflect the experiences, priorities, and values of people living with dementia and care partners. Decision-making for dementia care involves more than healthcare delivery and is influenced by a complex network of inputs from family members, care partners, providers, and health systems. Further work is needed to translate the core concepts of goal-concordant care from focusing primarily on end-of-life care and medical decision-making to the broader context of dementia care.



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