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Title

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Journal

Health Affairs Scholar, 3(1)

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Publication Date

2025

DOI

10.1093/haschl/qxae167

Peer reviewed

Family physicians' perspectives on outcomes, processes, and policies in dementia care

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Abstract

The rapid rise in numbers of people living with Alzheimer's disease and related disorders (ADRD) poses major challenges to health systems and policy. Although primary care clinicians provide ongoing medical care for 80% of affected individuals, they face persistent barriers to providing high-quality dementia care. We conducted qualitative interviews with family physicians ($n=20$) to understand what core outcomes they consider most important and what care processes and systems and policy strategies they propose to achieve them. Participants identified processes and outcomes pertaining to their relationships with patients and families, involvement in overall medical care, and efforts to mitigate harm as key components of dementia care. Participants also identified overarching patient care values: making active efforts to maintain continuity in the doctor-patient-family relationship, communicating clearly, building and sustaining trust, and responding to health-related social needs. Policy recommendations included work to create health care systems capable of providing comprehensive dementia care, full integration of caregivers into psychosocial care and medical management, adjustments to care cadence, and payment models that support team-based primary care. Findings could help refocus care improvement efforts on implementing the vital conditions for optimal health that can be achieved in primary care and sustained through the course of dementia.

Lay Summary

What are the core outcomes that family physicians consider the most important in their care of people with dementia, and what policy and practice strategies might be implemented by family physicians and their practice organizations to better align their values with practices and outcomes of dementia care?

Key words: dementia; primary care; caregivers; clinical outcomes; health systems strategies; policy; quality; family physicians; family medicine.

Introduction

The rapid rise in numbers of people living with Alzheimer's disease and related disorders (ADRD) poses major challenges to health systems and policy.¹ Although approaches to diagnosis and management have been defined largely by ADRD specialists, primary care clinicians are often the first and only point of care for patients with suspected and confirmed ADRD.^{2,3} A recent survey from the Alzheimer's Association found that 82% of primary care clinicians identified themselves as frontline providers of dementia care.⁴ Despite their critical role, primary care clinicians face persistent barriers to providing high-quality dementia care and are often expected to adopt standards of diagnosis and management

for which they are unprepared and structurally unable to deliver. The barriers to diagnosing and managing dementia in primary care are broad and well documented: insufficient knowledge, training, and confidence in diagnosis, time, resources, and access to or awareness of community services.⁵⁻¹⁰

Alignment of clinicians' goals for the care of their patients with those of their organization and the design of reforms is an important factor in health care improvement.¹¹ Yet, the voices of primary care clinicians themselves, particularly family physicians, who, as of 2019, comprised the largest fraction (nearly 40%) of the primary care workforce,¹² have been largely missing from the dementia care conversation, especially their perspectives on policy interventions that could

Received: July 9, 2024; Revised: August 5, 2024; Accepted: December 5, 2024

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improve care. Family physicians take an approach based on the values and practices involved in creating long-term and trusting relationships with patients, attending to social and community determinants of health, being the first point of contact in the health care system, helping patients navigate the health care system (including coordinating care with specialists), identifying additional needed services, and considering the impact of the patient's health on their family.¹³

Inductive analyses of family physician perspectives are necessary to complement an existing literature that largely focuses on barriers to care and patient and/or caregiver perspectives. From qualitative interviews with family physicians from diverse practices across the United States, we identified and characterized the outcomes valued most in their care of people with dementia, and the systems and policy strategies they propose to achieve those outcomes. Although we did not directly elicit challenges to achieving these outcomes, as challenges have been well documented in the literature, we did learn about challenges through their responses. Findings from this study can help refocus health system improvement efforts on implementing the vital conditions for optimal health and wellbeing that are valued and achievable in family medicine, and that can be sustained through the course of dementia.

Data and methods

We conducted 20 semi-structured interviews and a demographic survey with family physicians to explore their viewpoints on goals, priorities, and valued outcomes in the care of people with dementia and strategies to overcome barriers. Study participants were US-based family physicians across diverse settings, including primary care clinics, hospitals, and long-term care facilities. Family physicians were recruited in collaboration with the American Academy of Family Physicians (AAFP). This study was approved by the University of California, San Francisco, Institutional Review Board. We followed guidelines from the Standards for Reporting Qualitative Research.¹⁴

Data collection

The AAFP provided a list of potential participants based on their leadership or affiliation roles within the organization. We emailed 39 family physicians and recruited 20 respondents for interviews over video conference. Between January and April 2024 a medical anthropologist (A.B.S.) conducted interviews after obtaining verbal informed consent. Interviews lasted 30–45 minutes and were audio-recorded and professionally transcribed.

Interview domains were developed by a multidisciplinary team that included a medical anthropologist, a geriatric psychiatrist specializing in health care for dementia, and leaders and researchers at the AAFP. This process ensured that the interview guide covered areas important to understanding the experiences and needs of family physicians in the care of people with dementia and that responded to the primary goals of the study, which were to understand outcomes that are most important to family physicians. Final domains included goals and priorities in the care of people with suspected dementia and dementia, outcomes most important in the primary care of dementia, sources of information and training about dementia, scope of practice, patient and family priorities, improvement strategies, and case examples. Following each interview, a case summary was

created using a structured template to document notes summarizing responses. The interviewer also documented initial ideas about patterns in the data to help develop the codebook.

Analysis

Transcripts were uploaded to ATLAS.ti¹⁵ qualitative data analysis software. We created a preliminary codebook using the case summaries and interview guide and iteratively updated the codebook as we coded the transcripts both deductively and inductively. We double-coded 15% of the transcripts and discussed and resolved disagreements in coding throughout the process. During the process of coding, we achieved thematic saturation, which led us to close recruitment to the study. Codes were organized into themes that expressed family physicians' values, outcomes they hoped to achieve, processes to achieve them, and policy/practice strategies proposed to achieve these outcomes.

Table 1. Participant and practice characteristics.

Measure	n (%)
Sex/gender	
Female	12 (60%)
Male	7 (35%)
Self-described/gender-nonconforming	1 (5%)
Race ^a	
White	15 (75%)
Black	3 (15%)
Asian	2 (10%)
Middle Eastern	1 (5%)
Other	1 (5%)
Ethnicity	
Hispanic/Latino	2 (10%)
Title	
MD	19 (95%)
DO	1 (5%)
Years in clinical practice	
0–10	2 (10%)
11–20	11 (55%)
21–30	5 (25%)
31–40	2 (10%)
US region	
West	7 (35%)
South	2 (10%)
Midwest	3 (15%)
Northeast	5 (25%)
Geography ^a	
Urban	11 (55%)
Rural	7 (35%)
Suburban	1 (5%)
Micro-urban	1 (5%)
Other	1 (5%)
Practice setting ^a	
Accountable Care Organization (ACO)/value-based mechanism	6 (30%)
Federally Qualified Health Center (FQHC)	6 (30%)
Community health center (CHC) or community practice	4 (20%)
Private individual practice	2 (10%)
Private group practice	4 (20%)
Academic	4 (20%)
Rural health clinic/center	2 (10%)
Hospital practice	1 (5%)
County health department	1 (5%)
Direct	1 (5%)
Other	1 (5%)

n = 20.

^aParticipants could identify more than 1 option.

Results

Participant demographic and practice characteristics are reported in Table 1. Of 20 participants, 12 identified as female, 7 as male, and 1 as gender-nonconforming. Fifteen participants were White, 3 Black, 2 Asian, 1 Middle Eastern, and 1 “other.” Two participants identified as Hispanic or Latino. Eighteen (90%) had been in clinical practice between 11 and 40 years, while 2 (10%) had been in clinical practice for 10 years or less. Participants could indicate more than 1 practice setting, including Accountable Care Organizations (6), Federally Qualified Health Centers (6), private group (4) or individual (2) practice, academic practices (4), rural health clinics (2), hospital practice (1), and county health department (1).

Outcomes and processes

Family physicians identified the following outcomes as most important to them when caring for patients with dementia and their families and shared approaches and processes to achieving these goals. We provide exemplary quotes to illustrate each outcome. Although we organize outcomes by themes (Table 2), many overlap, most notably the need to engage family, a focus on safety across many domains, and the emphasis on attending to whole-person wellbeing.

1. **Sustained relationship.** Family physicians identified several outcomes that centered on their rapport and communication with patients and their families, as well as their holistic understanding of patient/family needs within the contexts of their lives.

(a) **Eliciting and fulfilling patient and family wishes and goals.** Family physicians discussed achieving this outcome by initiating goals of care conversations with patients, especially during the early stages of the disease when patients could describe their own priorities, often centering on maintaining independence and function. Challenges to supporting patient goals included first presentation at late dementia stages, language and health literacy factors, and economic impediments (eg, inadequate insurance or lack of access to resources).

Participant 13: A lot of times these are patients or families that I know, so I'm able to have an easier discussion figuring out what are your goals of care here? What is important for you? Is it important for you to be able to stay in your home,

and how do we help meet that? What kind of support do you need?

(b) **Maintaining quality of life.** Quality of life was viewed as a central outcome related to optimizing patients' sensory function (hearing, vision), social connection, care setting, nutrition, and activity. This included making sure the patient is well-cared for at all stages of the disease. They mentioned elements of care related to quality of life, such as finding ways to address patient needs when personal/family resources are limited and facilitating resource connections.

Participant 12: The biggest [outcome] is quality of life, no matter what phase [of dementia]...As they get moderate to severe [dementia], quality of life changes and is very much dependent on the support services they have around them. In my patients with severe dementia, we need to make sure that we have nursing assistance, family assistance. Or if they're living in a facility, making sure that facility is clean, safe, and appropriate. True outcomes, to me, all circle around where they are in the world.

(c) **Supporting family.** To support family, family physicians listen to and elicit concerns, actively “check in,” and promote openness in communication. They also discussed setting family expectations, addressing family members' health concerns and needs, and educating families about dementia, necessary health care, and the system of care, including how families can get paid as home health attendants. They reported a need to translate specialist recommendations into specific care plans, support families around managing behavioral symptoms, and identify supportive resources not typically provided within health care systems. Lack of family involvement posed challenges to family physicians, as did difficult family dynamics (eg, too many voices or conflicting priorities), unrealistic expectations, and lack of ability to understand or implement the care education provided.

Participant 17: It's also watching out for the caregivers, because I've had the privilege of taking care of multiple generations where the caregiver is also my patient. Even if they're not, just asking, are you getting a break? How are you handling things? What's going on? ... I've told more than 1 spouse that your husband or wife is going to be in the hospital. I don't need you in the hospital with them because you're so exhausted.

Table 2. Outcomes important to family physicians in dementia.

Important outcomes
Sustained relationship
Eliciting and fulfilling patient and family wishes and goals
Sustaining quality of life
Supporting family
Accountability for overall patient care management
Proactive and continuous monitoring and management of symptoms, wellness, medications, and preventative care
Managing comorbidity
Avoiding harm
Identify and manage safety risks
Avoid crisis-based hospitalizations
Attend to the burden of tests and treatments on the patient

2. **Accountability for overall patient care management.**

Family physicians identified several outcomes related to medical care of the patient, including both dementia symptoms and other health conditions, for which they considered themselves accountable.

(a) **Manage health proactively and continuously: symptoms, wellness, medications, and preventative care.** Family physicians recognized a responsibility to take the initiative in monitoring symptoms and signs to ensure that the patient is well-cared for. They reported checking skin, weight, appetite/food and fluid intake, sleep, and monitoring for fall risk. Preventative-care goals included ensuring that patients are current on

vaccinations and attend annual wellness exams. Medication management priorities included decreasing medication burden as disease progresses, managing polypharmacy, and monitoring appropriate use of medications.

Participant 16: Monitoring their symptoms, and when it starts getting to the time where the patient's potentially having some safety issues, whether it's wandering or frustration and anger, or what the family members are seeing...it's a lot of monitoring. And it's super unrewarding as a physician. Because we're so trained into treating and curing, and this is really just a lot of check-ins with no great answers of treatments. It's maximizing the resources that we have available to us to make sure that everybody is getting the support and care that they need.

- (b) **Attend to comorbidity management.** Managing medical risk and comorbidities (eg, diabetes, hypertension) was considered a key primary care responsibility, but called for more complex coordination with other clinicians involved in the patient's care as well as active coaching for family in supporting medical management at home. They noted that achieving this outcome could be difficult, resulting in avoidable harms, such as uncontrolled comorbidities and poor medication adherence. Challenges reported included families' absence (for patients living alone) or caregivers' inability to learn when and how to report new symptoms and mediate medical recommendations at home.

Participant 14: We always treat everything else that's going on with them; it could be their diabetes, their hypertension, or other problems. Our goal is trying to keep those things under as good control as we can. That's core to my job.

3. **Harm avoidance.** Family physicians identified several outcomes related to avoiding harms common in dementia.

- (a) **Identify and manage safety risks.** Areas of safety concern included risks of medication mismanagement, driving, and patients' unrestricted access to guns. Mitigating these risks was recognized as an important target. Active safety efforts included teaching family about safety risks, scheduling more frequent visits, involving Adult Protective Services when necessary, and considering home safety and the need to move to a supervised care setting.

Participant 17: Safety comes into it again. I don't want somebody breaking a hip because we know how many more problems that piles on top of things afterwards. Are they safe in whatever environment they're in? You're taking car keys away, which I know is really hard. So all of those types of things. And again, you've got to have family support with some of this stuff, otherwise it's not going to work.

- (b) **Avoid crisis-based hospitalizations.** Family physicians stated the importance of early recognition of signs of illness that might lead to hospitalization (eg, urinary tract infections [UTIs]) and the importance of seeing patients regularly to achieve this outcome. They identified the need to educate family

members about medical management at home and the significance of caregiver health literacy.

Participant 4: I always try to help families not end up in the hospital unnecessarily...often [the patients who do] will decline [there]. Helping families to have plans of what to do, how to notice [non-specific signs of illness such as] when [the person with dementia] is not as communicative [and can't communicate their symptoms in words]. If something seems off, if they might have a UTI, preventing that stuff before it becomes a hospitalization event.

- (c) **Attend to the burden of tests and treatments on the patient.** Family physicians discussed the need to assess the value of tests and treatments relative to stage/severity of dementia. They sought to reduce the burden of testing and routine screening through shared decision-making—for example, avoiding cancer screenings in later stages of the disease, thinking about what clinical actions would make the most difference, and avoiding invasive procedures.

Participant 11: Do we still need to be doing screenings for X, Y, or Z, breast cancer, lung cancer, colon cancer? I think the question becomes, are you going to treat it? It depends on where they are in the progress of their dementia. Even if you're not going to treat it because, say, their dementia is progressing quickly, sometimes it's still helpful to know, to be able to explain a pain that they might be having. I don't know that I would put somebody with advanced dementia through a colonoscopy, but if they have a breast lump, I might do a mammogram to give a sense of, is that likely breast cancer or not? So that we are understanding and helping to prepare the family on what might come with that?

Cross-cutting and overarching approaches to achieving what Family Physicians want

Several approaches to achieving the desirable processes and outcomes described by family physicians were cross-cutting themes that can be used to guide how clinicians are taught to manage patients with dementia, and how health systems frame priorities in care delivery. Key cross-cutting themes included the importance of trust, with participants emphasizing the importance and role of trust and enduring relationships with patients and families, a related theme prioritizing continuity of care, active and strong communication, and addressing unmet health-related social needs, health inequities, and disparities in the populations they serve. In [Table 3](#) we provide exemplary quotes illustrating these cross-cutting themes.

Strategies, solutions, and policy

Based on the desirable clinical outcomes, goals, and priorities expressed by family physicians, we asked them to identify strategies that could help them better provide high-quality dementia care, given known barriers and constraints. Details of family physician-recommended strategies and exemplary quotes are shown in [Table 4](#). At the community level, they focused on decreasing stigma about dementia, community education, and increasing resources—for example, accessible nursing and assisted living facilities. At the health systems level, they highlighted the value of improving electronic health records, including cross-system interoperability; adjusting payment models to

Table 3. Cross-cutting themes.

Theme	Exemplary quotes
The importance of trust	Participant 8: When you first meet, you're a total stranger to this patient. Then it's kind of like being in a family. Like, the more you can...lean in and be there for someone, the more likely they are to trust you. That's the ultimate goal, to be able to show that, and to use my brain for the science stuff, but then to use my heart for the spiritual stuff. Participant 15: Cases where it went well is we had good alignment with what the patient wanted, the family understood that, and what I was able to provide. We had a trust relationship, and we had great communication and partnership. Regardless of the outcome, it was a good path to get there.
Continuity of care and relationship with family physician	Participant 5: I think for the family physician, it's the long-term relationship, right? In my experience, being here 19 years now, I've had enough couples now who started off fine, and now have lived through this...as they see the dementia coming, and then they admit that it's here. Then you try to get them to take medicine or not take medicine, whatever it is, and working through how the end of life is going to look for this and where that's going to happen, whether that can happen at home or not. Participant 13: I think we're in a unique position a lot of times where we've known these patients for a longer period of time and have that longitudinal relationship established that allows us to have some of the conversations in a different way than would be had with neurology. I feel like a lot of times it's translating a lot of the medical terminology and just being able to communicate with the patients, somebody who's has a trusted relationship.
Strong communication	Participant 8: I think if I drop the ball on that from a communication perspective where the patient felt like they were abandoned, or they're just feeling like the care is uncoordinated, that would be disappointing to me. I'd feel like I let them down. I do try to, even between visits, I think it's important to keep your pulse on how things are going with your patients. Even if it doesn't involve an E/M code, a quick phone call or a quick message can make a world of difference. Participant 9: Just spending time talking to them.... Being really honest and upfront with what's likely to happen. Prognosis. I remember early in my career thinking that people would get upset when I gave them bad news and, actually, most of the time, people really appreciate the fact that I'm direct about what's going to happen or what is likely to happen.
Addressing health inequities and disparities in the population they serve	Participant 4: For families, particularly minoritized, marginalized communities that are not necessarily being given all of the resources for many things in their life, [they] are right to be suspicious, like, making sure that you are so forthright and building that trust because my patients have every right by experience to believe that maybe we're hiding something from them or not giving them something that would actually help them, and that maybe we know something or there's something we could do, but because they're Black or Brown, because they don't speak English, because they're immigrants, or undocumented, or poor, maybe we're not providing that. Participant 19: I'm in a community where social drivers of health are very heavy, so people don't necessarily have transportation. They don't necessarily have a caregiver at home. They don't necessarily have those resources that [large urban center] has.... So we're often creative. No, we're not going to have all of those support systems that a larger metropolitan would have.

Abbreviations: AAFP, American Academy of Family Physicians; E/M, Evaluation and Management.

accommodate the greater demands of caring for people with dementia, including more time with patients; increasing availability of dementia specialists; and broader access to social services. At the practice level, they articulated the importance of strengthening care teams with more geriatric mental health capacity and strengthening resources available to rural practices. In the clinician domain, they discussed opportunities for education and mentorship and harnessing informal connections with specialists—for example, e-consult pathways. At the patient/caregiver level, they focused on continuity of care, communication, and providing disease education.

Discussion

Values and outcomes

Family physicians' involvement in dementia care spans assessment and diagnosis, inclusive of referrals to specialists as needed, along with disease and comorbidity management. Barriers to providing high-quality care have been extensively studied, from both specialists and primary care perspectives.^{6-10,16,17}

Outcomes in dementia care have been primarily studied from the perspective of patients and caregivers.¹⁸⁻²⁰ In this study, we took an inductive approach to elicit family physicians' goals for ADRD care, the processes and outcomes they prioritize, and strategies they identify to achieve their desired outcomes. Many of the outcomes reported focused on the importance of relationships, taking a holistic view of the patient's health and wellbeing, individualizing the cadence of care, and minimizing harm, rather than on diagnosis and medications for ADRD. These findings are consistent with the core values of family medicine that focus on the whole person, intergenerational care, and the importance of relationships and trust. Notably absent from family physicians' perspectives were priorities focused on proactive or "early" dementia detection and the use of biomedical treatments for dementia, including novel therapeutics (eg, anti-amyloid antibodies), although respondents clearly recognized that earlier diagnosis fosters patient inclusion in care decisions. The dimensions of early detection and novel biomarkers and therapeutics lay outside the framework of goals that mattered most to the family physicians we interviewed, while a preventive orientation

Table 4. Strategies and policy recommendations.

Domain	Family Physician-identified strategies	Exemplary quotes	Health services and policy recommendations
Community	<ul style="list-style-type: none"> Public education about dementia to reduce stigma and increase awareness Accessible and increased resources for aging population (eg, more nursing/assisted living facilities) 	<p>Participant 18: “Working together with public health departments that are local to identify what are hyper-local resources for patient education that we can delegate from a primary care standpoint [...] I can’t do everything, but I can point the patient to reliable resources that I know and have vetted for them.”</p> <p>Participant 16: “I have an app for which drugs to prescribe and the dosage—is there just a better way of really activating the community resources for patients that they and their family members really need. That’d be so helpful with a lot of parts of medicine. That’s just not something that’s at our fingertips in our current health system and our model.”</p>	<ul style="list-style-type: none"> Work with local government entities (eg, city or county council) to promote Dementia Friendly Communities status Engage local community-based organizations (aging, dementia, and special populations service agencies) in community event planning (eg, “Dance with Dementia,” a Sunday public music and dancing event in a local park, engage religious community leaders, art shows by people living with dementia) Community-based education about dementia, elements of good care, community and clinical services available
Health system	<ul style="list-style-type: none"> Improve electronic health record (EHR) interoperability and usability for dementia-specific care Implement new payment models (eg, to cover more time with patients during appointments) Improving the availability of dementia specialists Broaden accessibility of social services and make it easier for clinicians to identify relevant resources (eg, apps) Interdisciplinary care model 	<p>Participant 7: “Not everyone uses the same EHR platform, and even if you do, my understanding is, you have to, as a health system, decide to pay for that additional interoperability. So bigger health systems can do it, but the smaller health systems don’t have the resources to pay for something like that.”</p> <p>Participant 3: “It applies to dementia, but it also applies to many other conditions, is simply getting away from this concept of fee for service in paying us for doing things, rather than taking care of people, right, and all of the kind of things that get in our way because that’s the way the system works.”</p>	<ul style="list-style-type: none"> Promote progress toward Age-Friendly Health Systems certification Negotiate/specify responsibilities of primary care clinician vs specialist clinicians vs other team members in caring for people living with dementia and families Promote awareness of dementia-capable health systems model Establish local system metrics for assessing dementia care capacity, and fill identified gaps Reward clinicians for meeting dementia care–quality measures (eg, Merit-Based Incentive Payment Systems [MIPS] or Dementia Capable System metrics) Implement care navigation (eg, the Guiding an Improved Dementia Experience [GUIDE] model and chronic care management) Innovate around development of chronic care teams, eg, community health worker roles to provide care navigation with Medicare reimbursement
Practice	<ul style="list-style-type: none"> Build and strengthen teams with geriatric mental health support capacity Have in-clinic specialists in primary care settings Strengthen team-based care 	<p>Participant 7: “Teams are important. Building up the primary care workforce, the clinician workforce. So physicians and physicians’ assistants would help because those of us who are still in continuity primary care are super stretched thin because of our panel sizes.”</p> <p>Participant 18: “The problem in a rural area, mental health is really not a resource around here, and you just can’t get them in there. They just don’t have the time or the staff to do that.”</p>	<ul style="list-style-type: none"> Tailor education to practice setting Web-based Continuing Medical Education (CME) offerings Better define roles of cognitive disorders specialists Engage cognitive disorders specialists in collaborative care with primary care clinician
Clinician	<ul style="list-style-type: none"> Dementia education training and mentorship (eg, externships, AAFP toolkit) Foster more informal connections with specialists (eg, streamlined e-consult pathways) 	<p>Participant 7: “I have certain specialists who I really, really love that through either communication with them about other patients or just the notes that they send me, I have learned their pattern of care, and can then implement it. So basically like an apprenticeship, just watching the sub-specialists do it.”</p> <p>Participant 15: “The third resource would be the ‘text a friend’. I had some good friends who were neurologists and were willing to be on speed dial. So I would say, ‘I have a case. Can I run it by you?’ And we might do it by text or by phone.”</p>	<ul style="list-style-type: none"> Tailor education to practice setting Web-based Continuing Medical Education (CME) offerings Better define roles of cognitive disorders specialists Engage cognitive disorders specialists in collaborative care with primary care clinician

(continued)

Table 4. Continued

Domain	Family Physician-identified strategies	Exemplary quotes	Health services and policy recommendations
Patient/care partner	<ul style="list-style-type: none"> • Maintain open and consistent communication with patients and families • Provide disease education, tailored for communication level • Early and continuous involvement of family in caregiving to avoid hospitalizations and address functional decline 	<p>Participant 4: “I never would imagine that I would be seeing a patient in isolation. That’s why when I have a patient who has dementia and worried about cognitive deficit and family hasn’t been engaged, I will push hard to get family in there. Most of the time there is family that cares about the patient. It’s not that they don’t. It’s that they either didn’t recognize it or they’re in extreme poverty and missing even a few hours of work is devastating.”</p> <p>Participant 5: “It’s probably better to talk about dementia in an open manner with the patient no matter what level they’re at. At some point, the level is going to be bad, and they won’t understand it. I don’t call it dementia. I call it memory problems, to take out the trigger word because that is a trigger word for many elderly.”</p>	<ul style="list-style-type: none"> • Public health efforts: awareness building using existing channels (eg, Alzheimer’s Association, Centers for Disease Control and Prevention [CDC], Building Our Largest Dementia [BOLD] Infrastructure for Alzheimer’s Centers) • Education about brain health to destigmatize dementia (eg, focus on biomedical education) • Teaching patients and families about elements of care • Payment models to support ongoing and continuous communication with families • Teaching clinicians about components of “dementia-capable care” tailored for local resources

Abbreviations: AAFP, American Academy of Family Physicians.

to risk reduction, proactive monitoring, attention to managing the burden of care, and family involvement were paramount and strongly expressive of the values of family medicine as a primary care discipline.²¹ We know from our and others’ prior work that clinicians across primary care settings need more time, institutional support, and resources, including evidence of relevant benefits, to embrace earlier detection of dementia as a goal. Furthermore, recently introduced and novel diagnostics (eg, blood-based biomarkers specific to Alzheimer’s disease) and therapeutics (eg, anti-amyloid antibodies) are creating new pressures for adoption that are not necessarily aligned with the goals of whole-person care articulated by family physicians. If these approaches are to be integrated, they will require new definitions of the roles, interactions, and collective responsibilities of primary and specialty care clinicians, especially in the context of managing the complex challenges of patients’ health, well-being, and social connectedness.

Policy implications

Our findings suggest the following policy considerations. Additional recommendations are highlighted in Table 4 alongside the family physician-identified strategies to achieving their desired outcomes. These recommendations were developed by our team as policy recommendations that reflect the family physician-identified strategies, needs, and experiences to show a breadth of possibilities that exist.

1. Develop a coherent health care delivery framework for ADRD.

Although family physicians in our study recognized their important role in the care of patients with ADRD and discussed many aspects of clinical care and examples of desirable clinical outcomes, what they found most meaningful was considering the patient as a whole person experiencing a progressive loss of agency, situated within a family and community

care system. They articulated that this system must be activated on behalf of the patient and saw themselves as playing an important part in this: working to understand the patient’s life in context as they tried to avoid harm and maximize quality of life. A commitment to the whole patient, and to making judgments based on patient and family needs, was clear even in advance of reimbursement opportunities. This finding highlights a need to expand the types of data available to help clinicians plan care, and what “counts” in developing evidence and measuring outcomes. These findings highlight the strengths that family physicians bring to dementia care, as well as the importance of attending to how dementia is experienced beyond the brain, by clinicians, patients, and families.

2. Develop dementia-capable health systems.

Our results highlight the need to further articulate, within the scope of primary care, what constitutes a dementia-capable health and social care system,²² and the supportive policies most critical to achieving the outcomes that family physicians identified. For example, dementia-capable health systems must work to ensure continuity of care, an area that family physicians considered central to their work. Team-based care is one path to improving continuity by enabling distribution of medical and social care activities within a coherent practice structure, a change that requires investment in new care structures.²³ Demands on health care systems challenge the balance between timely access when a patient needs care and availability of their own clinician, a key component of trust building for effective longitudinal care. Evidence-based care-navigation programs, such as the Care Ecosystem and the Healthy Aging Brain Center program, are ways to achieve this integration of social and medical care.²⁴⁻²⁷ However, they may require more direct integration into primary care, with teams that operate on-site and health systems that compensate and recognize their value. The Guiding an Improved Dementia Experience (GUIDE) model,²⁸ built on care-

navigation principles and evidence-based dementia care–management programs, is designed to accomplish this integration and is currently beginning an 8-year Centers for Medicare and Medicaid Innovation trial.

3. Inform policy on a national standard of quality in dementia care.

Quality indicators for dementia care have been repeatedly proposed^{29,30} but none has become a national requirement. Five widely accepted assessment processes, focused on cognition, function, safety, dementia-associated behaviors, and caregiver needs, are incorporated into Medicare's voluntary Merit-Based Incentive Payment System measures for specialists (neurologists and geriatricians). In addition, the Assistant Secretary for Planning and Evaluation has articulated 14 care processes³¹ that characterize dementia-capable health systems, for which uptake data are minimal at best for all but one. Detection of cognitive impairment, the starting point for dementia-capable health care systems, has been measured in studies of uptake of the annual wellness visit (AWV) and its impact on dementia diagnosis rates.³² Recent Medicare claims studies report improvement in dementia diagnosis rates relative to earlier studies, but sizeable proportions of patients continue to go undiagnosed. Prevalence, as reflected in claims diagnosis rates, appears to have little motivating effect on health systems.³³ Findings about outcomes important to family physicians can help inform the development of national standards of quality in dementia care.

4. Integrating caregivers as full partners in care management.

In prior studies with family caregivers of people with dementia, we found that even experienced caregivers in a well-resourced medical environment did not always recognize the patient's key medical problems, what a prescribed medication was for, whom to contact when problems arise, what problems should prompt a call to a clinician, and what they did not know.^{34–36} Family physicians in our sample often referred to staying engaged with family to meet their needs, but did not describe systematic ways to teach families how to be partners in achieving clinical goals—for example, preventing crisis hospitalizations. These findings support the need to recognize that caregivers are the *de facto* providers of health care at home for people living with dementia, and for researchers and family physicians to co-design a systematic approach to studying and improving the clinician–caregiver partnership based on the individualized, whole-person approach highly valued by family physicians. Because not everyone has a family caregiver, additional attention is needed to systematically fund and train professional care managers in comprehensive dementia-capable care.

5. Adjusting the cadence of care for people with dementia, and policy interventions to address this need.

Following the previous implication, family physicians we interviewed were well aware of how responsibility for health care shifts from the person with dementia to family or friends who do not necessarily come equipped with the necessary knowledge, skill, or ability to take this on, especially when overall needs are complex. They shared the critical insight that family physicians, too, must take on additional responsibility to be alert to clinical signs that may not be noticed at home or reported (eg,

unexplained weight loss caused by dementia-related neglect of food intake). This necessitates family physician training to recognize common complications of dementia and to develop clinical vigilance strategies that can be applied at home by care partners. Many FPs discussed the importance of continuous contact, continuity, and more frequent check-ins and visits to address shifts in the cadence of care, setting up a schedule that reflects the vulnerability of the patient and moves the family physician into a more active role in monitoring and reporting. Prior work has highlighted the importance of structured communication at regular intervals for dementia care, with a single clinician organizing communication.³⁷

Family physician responses valued continuity of care and simultaneous attention to multiple domains of wellbeing and health: these can be foci for policy enhancements, some of which are already in place but underutilized and insufficiently incentivized to be adopted at the system level. These include reimbursable services, such as the AWV that calls for detecting any existing cognitive impairment (~30% uptake, with no formal requirement for cognitive measures)³⁸; the Cognitive Assessment and Care Plan Billing Code (minimal uptake)³⁹; and the GUIDE model demonstration under Centers for Medicare and Medicaid Innovation, designed to improve care navigation for patients and families.²⁸ Other new Medicare reimbursement options, although not specific to dementia care, have become available in 2024, including payment for caregiver training and education, state-recognized community health worker activities, enhanced cognitive testing codes, and a small new incentive payment for continuity of care billed on a per-encounter basis. Other policy initiatives on the table—for example, broad payment enhancements that support team-based care as the default model of primary care—could be realized through implementation of these new payment opportunities but would require substantial investment in human and technological infrastructure to implement. The reward would be the opportunity to achieve high-quality dementia care through structural organization and reimbursement for the holistic, relationship-centered, and continuous care that family physicians clearly value and work to achieve.

Limitations

Although our sample size was sufficient to reach thematic saturation, it is relatively small. Findings could be expanded by using the interview guide to develop a survey for a wider, more broadly representative sample of family physicians. Most family physicians interviewed were clinically mature practitioners, not those in early- or late-career stages. We could not consider health system or practice type as influences, another area for future exploratory work in a survey or larger, targeted qualitative study. In addition, all participants were connected in some way to the AAFP, whether as active members or in positions of leadership. This may have biased our sample towards family physicians with unusual interest in dementia and those more oriented toward policy interventions. Finally, when asked about outcomes they value, family physicians primarily framed their responses in terms of care processes; additional research is needed to further define measurable patient outcomes that can be linked to their implementation.

Conclusion

This study provides a qualitative foundation for thinking about policy needs and areas for further development to

help match the outcomes that family physicians identify as most important with practice and health systems capabilities. Future work can focus on how to operationalize practices that achieve the outcomes prioritized by family physicians and lower the barriers to optimal dementia care outcomes.

Acknowledgments

The authors thank the American Academy of Family Physicians (AAFP) for their essential contributions to this work. This report and the conclusions are those of the authors and should not be construed as the official position or policy of the AAFP.

Supplementary material

Supplementary material is available at *Health Affairs Scholar* online.

Funding

This work was funded by the Health Resources and Services Administration (HRSA) (grant 1 U81HP26494-01-00] of the United States Department of Health and Human Services (HHS) as part of an award totaling \$543 300, with 0% financed with nongovernmental sources. The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS, or the US government. For more information, please visit [HRSA.gov](https://www.hrsa.gov). This work was also funded and supported by the National Institute on Aging (K01AG059840; R01AG087166).

Conflicts of interest

Please see ICMJE form(s) for author conflicts of interest. These have been provided as supplementary materials. A poster based on this research was presented at the Academy Health Annual Research Meeting in Baltimore, MD in June–July 2024.

Notes

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