

Family physicians' perspectives on important outcomes and policies when caring for people with dementia

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January 2025

Background

The increasing prevalence of Alzheimer's disease and related disorders (ADRD) presents significant challenges to health systems. Primary care clinicians, often the first point of contact for patients with ADRD, play a crucial role in their care. Despite being frontline providers, primary care clinicians face numerous barriers, including insufficient knowledge, lack of training, and inadequate resources, which hinder the effective diagnosis and management of dementia.

Study Aims

This qualitative study consisted of semi-structured interviews with 20 family physicians across the U.S. to explore their perspectives on ADRD care. The study aimed to identify outcomes that primary care providers consider most important in caring for people with ADRD and propose strategies to enhance care quality.

Study Design

The study utilized a qualitative research design involving semi-structured interviews with 20 family physicians from various practice settings across the United States. These physicians were selected with the aid of the American Association of Family Physicians (AAFP), which provided a list of potential participants based on their leadership roles or affiliations within the organization. From the initial pool, 20 FPs participated in interviews conducted via Zoom between January and April 2024.

Interviews lasted between 30 to 45 minutes and covered domains such as goals and priorities in dementia care, valued outcomes, training and information sources about dementia, scope of practice, patient and family priorities, strategies for improvement, and case examples. Transcripts were analyzed using ATLAS.ti software, with themes identified related to family physicians' values and strategies for effective ADRD management.

Findings

From the analysis of the interview transcripts, several key themes emerged regarding the outcomes valued by family physicians in the care of patients with dementia:

1. **Relationship-focused Care:** Family physicians stressed the importance of building solid relationships with patients and their families. Providers value eliciting and fulfilling patient and family wishes and goals. Maintaining patients' quality of life was also viewed as important.
2. **Comprehensive Management:** Proactive and continuous management of both dementia symptoms and other comorbid conditions was identified as crucial.

3. **Safety and Harm Avoidance:** A priority was ensuring patient safety by monitoring potential risks like medication mismanagement, driving, and access to harmful objects. Family physicians also focused on preventing crisis-based hospitalizations by recognizing symptoms indicative of acute conditions early.

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.

Limitations and Future Directions

A limitation of the study is that the sample size was relatively small and consisted mainly of family physicians who had connections to the AAFP. The study did not explore variation across types of practices or health systems, which could influence caregiving approaches. These are opportunities for future research to validate our findings with primary care clinicians from a wider range of settings and disciplines.

This study points to the need for policy changes and system improvements to align health system operations with the clinical outcomes valued by primary care providers in ADRD care. Future research should focus on operationalizing these findings to enhance care delivery.

Policy Implications

The findings from the study suggest several policy considerations for improving ADRD care:

1. **Development of a Coherent ADRD Care Framework:** Policies should support the creation of a health care delivery system tailored explicitly for ADRD that addresses the need for holistic, continuous care and integrates patients' social and medical needs.
2. **Develop Dementia-Capable Health Systems:** A critical need exists to define and implement a dementia-capable health system within primary care settings.
3. **National Standards of Quality in Dementia Care:** Establishing and enforcing national quality standards for dementia care could help standardize care processes across systems and ensure consistent, high-quality care.
4. **Integration of Caregivers as Care Partners:** Recognizing caregivers as essential partners in the management of ADRD, policies should facilitate caregiver involvement through education, support, and formal inclusion in care planning and decision-making processes.
5. **Adjusting Care Cadence and Supporting Policies:** Policies should support adjustments in the cadence of care to reflect the progressive nature of ADRD.

Full Report

<https://doi.org/10.1093/haschl/qxae167>

This work was supported by the Health Resources and Services Administration (HRSA) [Grant 1 U81HP26494-01-00] of the US Department of Health and Human Services (HHS). Dr. Sideman was supported by the National Institute on Aging (K01AG059840; R01AG6087166). Dr. Al Rousan was supported by the National Heart, Lung, and Blood Institute (K23HL148530). Dr. Razon was supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through grant number UL1TR001860 and linked award KL2 TR001859.