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Dementia care across a tertiary-care health system: What exists now and what needs to change

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Abstract

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Objectives—This study explored the process of care for persons living with dementia (PLWDs) in various care settings across a tertiary care system and considers challenges and opportunities for change.

Design—Aimed at quality improvement, qualitative interviews were conducted with key stakeholders in dementia care across geriatric outpatient clinics, medical and psychiatric emergency departments, and the main hospital in 2016.

Setting and Participants—Forty-nine interactive interviews were conducted with a purposive and snowball sampling of health care professionals (physicians, nurses, social workers, administrators) and families in a large, academic healthcare system.

Measures—Qualitative interview guides were developed by the study team to assess the process of care for PLWDs and strengths and challenges to delivering that care.

Results—Key themes emerging from the interviews in each care setting are presented. The outpatient setting offers expertise, a multidisciplinary clinic, and research opportunities, but needs to respond to long waitlists, space limitations, and lack of consensus about who owns dementia care. The emergency department offers a low nurse/patient ratio and expertise in acute medical problems, but experiences competing demands and staff turnover, in addition to dementia not appearing on medical records which can impede care. The hospital offers consultative services and resources, yet the physical space is confined and chaotic, sitters and antipsychotics can be overused, and placement outside of the hospital for PLWDs can be a challenge.

Conclusions and Implications—Five key recommendations are provided to help health systems proactively prepare for the coming boom of PLWD and their caregivers including outpatient education, a dementia care management program to link services, internet-based training for providers, and repurposing sitters as elder life specialists.

Article summary

Clinicians and other stakeholders involved in care for dementia patients in a major health system suggest increased training and comprehensive models of care to optimize the quality and efficiency of provided care.

Keywords

dementia care; outpatient; emergency department; inpatient; health system

There are 50 million persons living with dementia (PLWDs) globally; this number is expected to double every 20 years as the older population around the world grows.¹ Because dementia is associated with increased risk of hospitalization, longer stays and readmission, functional disability, nursing home admission, and higher overall healthcare costs, the growth of this population poses a growing care challenge for health systems.²⁻⁵

Care is complex for PLWDs due to the variable symptom profile across PLWDs, limited options for effective treatment, and lack of training, education, time and resources among providers.⁶ The challenges of providing care to PLWDs in outpatient settings are suggested by the higher rates of potentially preventable hospitalization for conditions including urinary

tract infections or diabetes.^{4,7,8} Once hospitalized, impaired cognition and reduced functional status put PLWDs at increased risk for adverse outcomes.⁹ Additionally, “geriatric syndromes” such as falls, incontinence, delirium and functional decline are common during hospitalization.^{5,10,11, 12,13} Large health care systems often lack coordination with community resources and care settings.⁶ While coordinated and patient-centered care has been associated with reduced hospitalizations, delayed placement, and improved functioning and well-being for PLWDs and their caregivers, most health care systems have not invested in such coordination.^{1,13–16}

Given that dementia poses a growing challenge to health systems, we investigated barriers in the coordination of care for PLWDs at one of the highest ranked and largest hospitals in the United States (Michigan Medicine, #5 best hospital in the nation based on the U.S. News & World Report Honor Roll 2018–2019). In the current study, the “Michigan LEAn thinking for Dementia care” (M-LEAD) team interviewed key stakeholders involved in care for PLWDs throughout Michigan Medicine and explored current strengths and challenges to provision of care for these patients. We aimed to identify common challenges and opportunities for care improvement and suggest viable and scalable solutions to improve the quality of care of PLWDs and their caregivers.

Methods

The M-LEAD team, including dementia researchers and providers from the University of Michigan Schools of Medicine, Public Health, and Social Work, explored the process of care for PLWDs across the healthcare system spectrum of outpatient, inpatient, and emergency department care. Because the purpose of the study was quality improvement, the IRB deemed the project not regulated.

Encounters

First, the Data Direct database (internally accessible healthcare system database of all encounters) was searched to determine an approximate number of PLWDs seen within each level of care in 2016. Estimates come from billing data or clinician identified problem lists for a given encounter, thus likely an underestimate.

Stakeholders/Participants

Next, qualitative interviews were conducted from 2016–2017 with key outpatient, emergency, and inpatient setting stakeholders. The M-LEAD team developed the initial list of stakeholders from each site based on staff known to have a role in dementia care and who had worked at Michigan Medicine for at least one year. Stakeholders were asked to recommend additional people to interview. Stakeholders were recruited by email and included: clinicians (doctors, nurses); administrative and support staff (social workers, clinic directors, hospital security, hospital bed management); and family members of a PLWD who received care at the healthcare system. We used a broad definition of stakeholder (for example including hospital security and a lawyer involved in capacity decisions), and made every effort to include a wide array of stakeholders from across the medical system. In all,

49 interviews were conducted. Demographic information on the sample was not collected to maintain confidentiality as this information would be individually identifiable per the IRB.

Procedures

Stakeholders were interviewed by the project manager (A.L. a PhD psychologist with graduate training in qualitative methods) individually at a location they chose (e.g. office or common area). Interviews were recorded and transcribed with every effort to maintain confidentiality.

Stakeholders were asked to describe the structure of the care system within their unit, summarize the process of care for PLWDs and their families and identify key strengths and challenges of providing care for PLWDs. Probes specific to the care setting were used (e.g. outpatient stakeholders were asked about waitlists and follow-ups; inpatient stakeholders were asked about sitter use and patient disposition). (Interview schedules are provided in Supplementary Table 1.) A grounded theory approach was used whereby interviews were done iteratively with note taking and analysis informing the next round of interviews. Interviews were done in stages starting with outpatient, followed by emergency department, and finally inpatient. Stakeholder's interviewee recommendations were followed until saturation was reached. After interviews were completed in each setting, the team held an in-person meeting to review transcripts and identify key themes that emerged from the data. Potential differences among team members were resolved with discussion, resulting in general consensus. As our aim was to identify barriers to care coordination for PLWDs and identify scalable solutions based on existing strengths and challenges, we organized findings by care setting, describing the most salient, recurring themes identified by stakeholders relating to the process of care and strengths and challenges for inpatient, emergency, and outpatient care, respectively.

Results

Inpatient Care

Among patients aged 65 years old in 2016, 778 PLWDs experienced 2,646 admissions to the health system's main hospital (3.4 admissions per PLWD on average).

The process of managing care for PLWDs—Stakeholders noted that PLWDs were admitted for a variety of medical problems and dementia is “sometimes recognized, sometimes not recognized until it becomes a contributing factor to other things such as delirium or the inability of the patient to return to their prior setting of care.” Several hospital-based programs and services assist in care for PLWD. For example, “No One Dies Alone” provides a volunteer to sit with a patient at the end of life, while “Elder Life” volunteers spend 30 minutes twice daily with patients to prevent delirium, falls, and restraints and reduce length of stay. Additionally, the Psychiatry Consultation Liaison Service, a hospital team of mental health professionals (psychiatrists, a psychologist, and a nurse practitioner) provides a link between psychiatry and the medical/surgical services and considers cognitive impairment part of their routine assessment. While the primary team typically makes decisions and provides care for a patient with dementia, the Geriatric

Consult Service is sometimes consulted particularly in instances of delirium or an undeveloped discharge plan.

PLWDs may end up in the adult inpatient psychiatry (AIP) unit, although dementia is not a prioritized population for admission primarily due to disposition problems (difficulty finding appropriate community placement). The primary reason a PLWD is referred to AIP is agitation and this unit views their role as modifying behavioral symptoms with medications. The average length of stay in AIP was estimated by stakeholders to be 8 or 9 days, but some PLWD may be on the AIP unit for months (and such long stays create a reluctance to admit PLWDs to AIP).

Within the University Hospital, various strategies for managing PLWDs were described including: moving the person close to the nurse's station, using telemonitors, (over)use of sitters (e.g. for non-behavioral or medical tasks such as feeding ice chips to patients), use of electronic sitters (a staff member in another room who monitors patients via the speaker tower), "pulling the trigger on using antipsychotics quickly rather than trying other things", and "not thinking about the long-term and going for a short-term win...short sightedness of the overall care plan".

Strengths and challenges to Inpatient Care—Key strengths in the inpatient setting for dementia care include access to resources, geriatrics experts, and consultative services that are helpful for PLWDs. However, consultation tends to be more of an "after thought". Key challenges include the physical environment not being designed for PLWDs (e.g. lack of sunlight and open space to wander), disposition of PLWDs (particularly those with behavioral challenges), the overuse and expense of sitters/one-to-ones who are often used for menial tasks rather than engaging patients ("so you just have a stranger in your room that is not talking with you"), concern regarding electronic sitters scaring PLWD, antipsychotics and psychotropic medications being overused despite black box warnings, and distinguishing between delirium and dementia. Further, stakeholders described the interpersonal dynamic between providers and PLWDs could be dehumanizing, training in dementia is lacking, staffing is inconsistent, and providers have hypersensitivity to falls and time constraints. Select stakeholder quotes that illuminate these strengths and challenges are included in Table 1.

Emergency Department Care

Both the Medical Emergency Department (Med ED) and Psychiatric Emergency Services (PES) commonly see PLWDs. Among patients 65 years old in 2016, the Medical and Psychiatric Emergency Rooms saw 975 PLWDs during 1,427 encounters (1.5 visits per PLWD on average).

The process—In the ED setting, the first priority is determining whether an acute medical issue is present, though dementia is acknowledged as adding a "layer of complexity". Patients typically do not present with complaints of dementia and a diagnosis is not made in this setting—and thus the role of dementia care is viewed as indirect. The few PLWDs seen in PES stand out as "train wrecks" ("they have a lot of medical comorbidities, sometimes they come in kicking and screaming, sometimes nursing facilities say we can't take them

back- they are too agitated”). When a diagnosis of dementia is suspected, stakeholders stated that they try to determine the patient’s cognitive baseline and ability to participate in medical decision-making. PLWDs may not understand why they are at the hospital, accurately provide a medical history, or answer questions during the physical exam; thus, family members or long-term care staff are relied on to provide such information. Behavioral symptoms are managed by additional personnel (e.g. sitters, a bedside nurse to “deescalate and support” or orient the patient, security staff) and psychotropic medication when necessary for patient safety. However, given priorities within both the Med ED and PES, helping a patient with dementia “calm down might not always be the highest on our priority list...we often don’t have time”.

Strengths and challenges for Emergency settings—Strengths noted included patient safety, a low nurse to patient ratio, a PES 24-hour crisis line, and ability to determine the acute medical problem. Challenges include competing demands, dementia not being identified on the medical record, staff turnover and lack of training, and lack of awareness or availability for referral options. The Med ED was described as an “exceptionally unfriendly place for anybody with dementia” due to its chaotic nature, lack of natural light, staff turnover, and uncomfortable, disorienting environment. There was also discussion surrounding whose “issue” dementia was: is it a medical, psychiatric, or neurological issue and accompanying uncertainty about the appropriate admitting service. PLWDs were described as “hot potatoes” often sent back and forth between the Med ED and PES, with one stakeholder stating: “the facility doesn’t want them back, the family doesn’t want them back, and there’s no place to send them”. The challenges were summarized by this stakeholder, “We are extremely overwhelmed by the number of patients and the amount of work that needs to get done. And a patient with dementia or with delirium is extremely labor intensive and to do it in a humanistic way is time consuming”. (Key quotes in Table 1.)

Outpatient Care

The University Geriatrics Center includes several specialties involved in dementia diagnosis and care: Geriatric Medicine, Geriatric Psychiatry, and Cognitive Neurology. All three clinics refer patients to the neuropsychology program for cognitive testing. Among patients 65 years old in 2016, Geriatric Center outpatient clinics saw 2,903 PLWDs for 16,446 encounters (5.7 visits per PLWD on average). Of note, half of PLWDs seen within the health care system (ED or inpatient care) had not been seen within the Geriatrics Center clinics in the prior year, suggesting a potential underutilization of specialized outpatient care as a preventive resource.

The process—Stakeholders noted that outpatient visits focus on assessment and diagnosis (all clinics) or management of behavioral symptoms (geriatric psychiatry). In most clinics, family caregivers are an integral part of the clinic visit and help provide a patient’s history. Patients and family members from all clinics may be referred to multiple services (e.g. geriatric medicine, cognitive disorders, geriatric psychiatry, physical and occupational therapy, drivability assessments, visiting nurses, social work, palliative care) depending on needs. If a patient were admitted to the hospital, most providers are not the admitting physician but would monitor their progress once hospitalized and collaborate with their

inpatient colleagues. Regarding complex dementia-related behavioral issues, all clinics handle them but often without a clearly defined approach. Further, most stakeholders were not aware of any methods to avert potentially preventable hospitalizations or ED visits, and no one identified any formal performance goals or measures for their clinic or the health system related to dementia care.

Strengths and challenges—Major strengths of the clinics include multidisciplinary teams, skilled providers with diagnostic expertise and availability for follow-up visits. However, a number of challenges were cited: unclear role differentiation for the various clinics serving PLWDs, need for additional space, “no-shows/cancellations” and long waitlists. The outpatient stakeholders also described concerns regarding continuity of care across the health system and the inpatient experience for their admitted patients. (See Table 1)

Discussion and Key Recommendations

We explored the dementia care process across a tertiary care system from both stakeholder and family perspectives. Understanding strengths and challenges from this lens is critical as stakeholders will be relied upon to inform and deliver new care models and collaborate with colleagues across levels of care.

As opposed to a commonly used Delphi panel of predetermined experts, we sampled key stakeholders across the health system identified by the M-LEAD team and by other interviewed experts critical to the process of care for PLWDs. Prior work has largely employed retrospective chart review or prospective cohort studies to identify key challenges in hospital settings (e.g. falls, delirium)^{3,5,9–11}, or offered thought papers or clinical trials regarding improving care for PLWDs through integrative care models^{6,15–18}, many setting specific (e.g. home or primary care).^{14,19,20}

This study uniquely created thought experiments and inspired discussion among stakeholders (such as facilitating communication between clinic directors upon reviewing study findings). For example, one stakeholder told us, “After you brought [dementia care within our health system] to my attention...I started sort of thinking well is there a home for this population? And then I realized there really isn’t. And then I wondered well where would these patients be admitted? And that was totally up in the air...it’s not defined...that actually causes some tension that probably doesn’t need to happen. So if anything, your questions just sort of helped to identify for me that there’s a lot of opportunities here that clearly have to be defined.” Such discussions should be happening proactively in health systems as numbers of PLWDs are increasing.

Several caveats should be mentioned. Interviewees were important stakeholders within the healthcare system involved in dementia care, yet the information provided may not reflect the opinions or process of care for all. Generalizability may be limited in examining one rather than multiple healthcare systems. The VA and NHS, for example, have standards of care applied across systems, while smaller healthcare systems may deliver more integrated geriatric care, but our findings suggest potentially useful lessons that can inform the work of other health systems and researchers.

Recommendations

The M-LEAD team developed five strategic recommendations (Table 2). First and overarching, health systems should prepare for the coming “boom” of PLWD, including plans for staffing, specialized training, and new technologies. As part of this training, providers should be aware of appropriate referrals and resources and how to access them, involving family caregivers early in the process.¹⁷

Second, we recommend creating a dementia care management program to better link services across the health system for complex/costly patients. Providers and families alike consistently reported not knowing where to turn or what referral to make within the large health system. Having a clear collaborative care management program could reduce waitlists and help patients receive efficient and more specialized care.^{15,18,21} As most PLWDs are seen within primary care settings, it is important that their providers can point PLWDs and caregivers towards appropriate sources of community-based education and support. Attending to the extensive non-medical needs of these patients and their families cannot be “just one more thing” primary care providers are expected to provide.

Third, providing separate outpatient education programs for families (perhaps as part of a care management program) and primary care physicians could further reduce preventable ED visits and hospitalizations. Enabling primary care physicians, caregivers, and patients to engage in open dialogue and be informed about the progression of the disease can help them proactively prepare for next steps rather than having important healthcare decisions occur in moments of crisis.¹⁹

Next, within Michigan Medicine and many other health systems, a number of web-based training modules are required for faculty and staff (e.g., research ethics, fire safety). We recommend the development of an engaging training and educational program on dementia care.²⁰ This training could encompass basic education on dementia and its symptoms, identifying delirium as distinct from dementia, and behavioral approaches to address challenging behaviors. This could be mandatory for new employees with required periodic renewal to ensure updated and standard training across professional roles and settings.

Our fifth recommendation is to repurpose sitter resources to elder life specialists, similar to child life programs available in many hospitals. According to our stakeholders, while “sitters” or “one-to-ones” were widely used, they were under-used as a resource to actually engage with patients (e.g. using their phone and not interacting with patients). Elder life specialists could be trained to tailor their approach to the needs of the PLWD including engaging activities, room modifications, and enhancing safety.

Conclusions and Implications

With the number of older adults with dementia anticipated to triple by 2050, health systems need to prepare for these patients and their families across the spectrum of care. These patients present challenges in both outpatient, emergency, and inpatient settings, making them both costly and resource-intensive patients. Optimizing quality and efficiency of care, individualizing dementia care, ensuring an adequate, qualified workforce, and developing

comprehensive models for dementia care, services, and supports were all key themes and recommendations from stakeholders.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1. Key stakeholder quotes regarding strengths and challenges of outpatient, emergency and inpatient dementia care

	Examples	Illuminating Quotes
Outpatient		
<i>Strengths</i>	Expertise and involvement of doctors and staff	<p>“the psychiatrist really being involved...a good ability to talk with caregivers”</p> <p>“a lot of experience and training within geriatrics [which is] unusual across the country as there’s a shortage”</p> <p>“the reason why we are so overloaded with referrals because we have some of the best doctors”</p>
	Multidisciplinary clinic	<p>“it’s one stop shopping...patients can be seen in all 3 clinics [cognitive disorders, primary care, geriatric psychiatry]”</p>
	Research opportunities	<p>“newer diagnostic technologies...links with the [Michigan] Alzheimer’s Disease Center for research opportunities”</p>
<i>Challenges</i>	“turf war” between clinics	<p>“the question is, who does dementia? Because there are three ways that you can come in...and that seems so inefficient because they don’t know where they’ll get in first so they’ll basically put in a referral for everyone and then you get a lot of duplicated, unnecessary care”</p> <p>“there’s not always a good link between the three...sometimes it’s more of a ‘turf war’ than it is a ‘let’s work on this together’”</p>
	Resources/space	<p>“time and costs really underlines everything that we face right now”</p> <p>“the demand is far greater than we can provide”</p>
	waitlist	<p>“we cringe with the thought of telling you we can’t get you in for another 6 months or 9 months”</p>
	Inpatient and long-term care concerns	<p>“[hospitals and long-term care facilities] learning how to actually deal with [behavioral issues] appropriately”</p> <p>“need to have well-coordinated care for dementia patients...physicians do not necessarily take outpatient physicians’ direction in terms of what medications have been used”</p>
Emergency		
<i>Strengths</i>	Patient safety and low nurse/patient ratio	<p>“we have a very favorable nurse patient ratio- on average each nurse has three patients” “not too many injuries that occur in our setting”</p>
	Determining acute medical problem	<p>“tenacity to get to the source of the problem and to make sure that we’re providing the safest care possible”</p> <p>“do a generally good job of determining if dementia is a likely diagnosis without the time and the resources to do a full evaluation”</p>
<i>Challenges</i>	Competing demands	<p>“We are extremely overwhelmed by the number of patients and the amount of work...and a patient with dementia or with delirium is extremely labor intensive and to do it in a humanistic way is time consuming”</p>
	Dementia not on medical record	<p>“It’s a comorbidity that may or may not be recognized. We suspect a lot of people have dementia who don’t have a formal diagnosis...it may or may not play a big role in what happens to that patient”</p>
	Staff turnover/lacking training	<p>“it’s difficult to keep people in the jobs...they turnover a fair amount...and if we don’t have the training every year there might be people who don’t have the training”</p>
	Unaware of resources	<p>“I don’t think we have a lot to offer- and that’s one of the frustrations- when you have somebody coming in and you don’t feel you have anything to offer them”</p>
Inpatient		
<i>Strengths</i>	Great resources and experts	<p>“dedicated team of folks who really want to do right by these patients”</p> <p>“highly skilled clinicians”</p>

Examples		Illuminating Quotes
Consultative services	Design	<p>“the care team, the geriatrics consultation team, the occupational therapists, all of the multidisciplinary team is invaluable”</p> <p>Geriatric and Psychiatric Consult Teams; Elder Life Program- provide interventions to reduce delirium, falls, restraints, length of stay; No One Dies Alone- someone to sit with patients at end of life; Music or pet therapy</p>
	Sitters	<p>“double rooms, confined environment, bathrooms aren’t ADA compliant, not a lot of daylight”, “chaos that is around them at all times”</p> <p>“lack of protected open space and resources to engage the patient”</p> <p>“we tried to limit the use of sitters but staff felt that was not safe...our expenses related to sitters have exponentially gone up...a never ending demand”</p> <p>“they will just be playing on their phones or reading a book”</p> <p>“the robot sitter is used when you want a safety eye...but no longer need a physical presence...most patients find them very disconcerting...they think they’re hearing voices coming out of the walls”</p>
	Overuse of antipsychotics and psychotropics	<p>“all the time we use chemical restraints...I have seen a lot of Haldol hangovers”</p> <p>“not thinking about the long-term and going for a short-term win”</p> <p>“they’re used to here’s a problem and here’s a pill or procedure to fix it. Well that isn’t possible with dementia...which is why we get caught in this scenario of giving antipsychotics when we know they’re not effective...we feel pressure to do something”</p>
	Distinguishing delirium	<p>“ongoing confusion about figuring out the etiology that might be causing it”</p>
	Disposition of patients	<p>“if they have behavioral problems it’s always a challenge...the nursing facilities now have eyes and ears in the hospitals...half the people transferred here [from facilities] had been in restraints or delirious, but if you look at the chart they will deny that”</p> <p>“rule of patients being 24-hours sitter free before a facility will admit”</p> <p>“sometimes it takes a crisis to get them to the next level of care and so we are the ‘wait/stop’ while we sort out those issues”</p>

Table 2.

Dementia care recommendations for tertiary-care health systems

Key recommendations:	
1. Proactively prepare for the coming boom of patients with dementia in health system	4. Health system provider training/education around dementia care (mandatory web training)
2. Dementia care management program to better link services across the health system for complex/costly patients	5. Repurpose sitter resources to elder life specialists (similar to current child life program) to provide engaging activities, room modifications, enhance safety, and training for family/staff
3. Outpatient education program for families and primary care physicians to reduce preventable ED visits and hospitalizations (e.g. UTI)	

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