Features of primary care practice influence emergency care-seeking behaviors by caregivers of persons with dementia: A multiple-perspective qualitative study

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Abstract
Background: Persons with dementia use emergency department services at rates greater than other older adults. Despite risks associated with emergency department use, persons with dementia often experience delays in accessing appropriate care, which may further exacerbate their health outcomes. Therefore, understanding the factors that influence emergency care-seeking behaviors in caregivers of persons with dementia is crucial for improving the quality of care and outcomes of these individuals.

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dementia and their caregivers often seek emergency services to address needs and symptoms that could be managed within primary care settings. As emergency departments (EDs) are typically sub-optimal environments for addressing dementia-related health issues, facilitating effective primary care provision is critical to reduce the need for, or decision to seek, emergency services. The aim of this study is to explore how features of primary care practice influence care-seeking decisions by community-dwelling persons with dementia and familial caregivers.

Methods: Semi-structured qualitative interviews were conducted with 27 key dementia-care stakeholders (10 primary care/geriatrics providers, 5 caregivers, 4 emergency medicine physicians, 5 aging service providers, and 3 community paramedics) from multiple health systems. Transcripts from audio recordings were analyzed using a thematic analysis framework to iteratively code and develop emergent themes. Features of primary care were also synthesized into lists of tangible factors leading to emergency care-seeking and those that help prevent (or decrease the need for) ED use.

Findings: Stakeholders identified eight categories of features of primary care encompassing the clinical environment and provision of care. These collapsed into four major themes: (1) clinic and organizational features—including clinic structure and care team staffing; (2) emphasizing proactive approaches to anticipate needs and avoid acute problems—including establishing goals of care, preparing for the future, developing provider—patient/provider—caregiver relationships, and providing caregiver support, education, and resources to help prevent emergencies; (3) health care provider skills and knowledge of dementia—including training and diagnostic capabilities; and (4) engaging appropriate community services/resources to address evolving needs.

Conclusions: Features of primary care practice influence decisions to seek emergency department care at the system, organizational/clinic, medical, and interpersonal levels, particularly regarding proactive and reactive approaches to addressing dementia-related needs. Interventions for improving primary care for persons with dementia and their caregivers should consider incorporating features that facilitate proactive family-centered dementia care across the four identified themes, and minimize those leading to caregiver decisions to utilize emergency services.

Keywords
dementia, Alzheimer’s disease, primary care, emergency department, caregiving, caregiver needs, decision making, acute care

Introduction
Alzheimer’s disease and related dementias pose medical and psychosocial challenges to patients, families, and the healthcare system. Almost 6 million individuals over the age of 65 in the U.S. live with dementia, a number expected to increase to 13.8 million by 2050 (Alzheimer’s Association, 2018; Alzheimer’s Association & Centers for Disease Control and Prevention, 2018; Hebert, Weuve, Scherr, & Evans, 2013). Persons with dementia access health care, including primary, specialty, and acute care services at a greater rate than those without dementia, resulting in increased health care expenditures (Alzheimer’s Association, 2018; Alzheimer’s Association & Centers for Disease Control and Prevention, 2018; Hunt, Coombs, & Stephens, 2018; LaMantia, Stump, Messina, Miller, & Callahan, 2016; Rosenbloom et al., 2018). For people living with dementia, emergency department
(ED) visits have been associated with increased risk for poor outcomes (e.g., delirium, falls, unnecessary testing) (Bass et al., 2015; Clevenger, Chu, Yang, & Hepburn, 2012; Gagnon-Roy et al., 2018; Hunt et al., 2018). Older adults with dementia are 51% more likely to have ED visits for potentially avoidable reasons, compared to those without dementia (Feng, Coots, Kaganova, & Wiener, 2014).

As researchers study ways of optimizing emergency care delivery for older adults with dementia (e.g., Parke, Hunter, Schulz, & Jouanne, 2019) more attention is being given to the important role of primary care providers (PCPs) in addressing both chronic and acute care needs. Studies about primary care for people living with dementia have traditionally focused on diagnosis and early disease management (Aminzadeh, Molnar, Dalziel, & Ayotte, 2012). A growing body of literature explores approaches to clinical care and caregiver support across the disease trajectory, but little emphasis has been placed on ways in which the provision of primary care itself affects care-seeking decisions—either from the perspective of those providing or those receiving the care (Austrom, Boustani, & LaMantia, 2018; Callahan et al., 2006; Gitlin, Marx, Stanley, & Hodgson, 2015; Gitlin, Maslow, & Khillan, 2018; L. A. Jennings et al., 2016; Lee et al., 2014; Netting & Williams, 1999; Reuben et al., 2013).

Familial caregivers are frequently responsible for making health care decisions on behalf of people with dementia, a role that increases with symptom and cognitive impairment severity (Karlawish, Casarett, Propert, James, & Clark, 2002; Menne & Whitlatch, 2007; Miller, Lee, Whitlatch, & Lyons, 2017; Miller, Whitlatch, & Lyons, 2016). There are many ways in which caregivers’ unmet needs influence care-related decisions, including whether and when to seek emergency services to manage care receivers’ acute medical or behavioral problems (Jacobsohn et al., 2019). As PCPs are the predominant source of medical care for 77% of community-dwelling people with dementia (Yang, Chang, Carmichael, Oh, & Bynum, 2016), it is important to understand the ways in which the features and characteristics of primary care influence these decisions, particularly for issues which could have been treated in a primary or urgent care setting. The aim of this study is to identify the features of primary care practice that influence emergency care-seeking when addressing acute health and behavioral problems experienced by community-dwelling persons with dementia, from the perspectives of multiple dementia-care stakeholders.

Methods

Study design

This qualitative study is part of a research program to develop interventions that prevent or lead to better emergency care services for older adults with dementia. The University of Wisconsin-Madison Institutional Review Board approved the study with a waiver of written documentation of consent. Study procedures and reporting were informed by the Consolidated criteria for Reporting Qualitative research (COREQ) criteria (Tong, Sainsbury, & Craig, 2013).

Recruitment

As part of a larger study assessing how unmet needs influence emergency care utilization for persons with dementia (Jacobsohn et al., 2019), we used purposive sampling strategies to
identify and select participants from key stakeholder categories identified a priori by the study team. Here, “primary care providers” refers to health care practitioners (physicians or nurses) working in internal medicine, family medicine, or geriatrics who treat older adults with dementia in their regular practice. Other key stakeholders included familial caregivers, emergency medicine physicians, and paramedics. Inclusion of these individuals was critical to our understanding as they experience the ways primary care practice influences acute care seeking outside of the primary care encounter. To gather an even wider range of experiences, we also included aging service providers (social workers) who work closely with older adults and caregivers in different social service settings (e.g., municipal human services departments, senior centers, healthcare systems). These perspectives, grounded in decades of case management and direct support for people with dementia and caregivers, provided insight into the prevalence of healthcare experiences and critical issues across the populations they served.

Potential participants in each stakeholder category were initially identified in coordination with affiliates at local dementia-related research, health care, and social service organizations. Opportunistic and snowball sampling were utilized to complete recruitment (Kemper, Stringfield, & Teddlie, 2003; Noy, 2008). Participants were then contacted via email, explained the purpose of the study, and given the opportunity to ask questions prior to scheduling the interview.

Data collection

Two researchers trained in qualitative methods conducted interviews in person or via telephone (average length 72 minutes) between September 2017 and August 2018. We interviewed participants in a setting of their choice: usually face-to-face in or near the interviewee’s workplace. All interviews were private and audio-recorded for transcription purposes. Most participants worked in Dane County, Wisconsin, which includes urban, suburban, and rural communities. Recruitment ceased once informational redundancy occurred in the data and no new codes were identified (Guest, Bunce, & Johnson, 2016; Sandelowski, 1995; Saunders et al., 2018). We compensated participants $50 for their time.

The study team developed a semi-structured interview guide informed by prior research, iteratively revised throughout the process to better achieve study goals and expand upon emerging themes (Corbin & Strauss, 2014). Transcripts were de-identified prior to analysis to ensure confidentiality.

Thematic analysis

We used a Thematic Analysis framework (Braun & Clarke, 2006; Braun, Clarke, & Terry, 2014; Nowell, Norris, White, & Moules, 2017) to code transcripts and identify meaningful data patterns. This iterative, reflexive, systematic method allowed us to look for themes based on participant experiences, influencing factors, and practices. Two interviewers independently analyzed each transcript, systematically identifying key ideas and insights. The codebook consisted of these inductively-derived codes. After completing an initial analysis of all transcripts, researchers revisited transcripts coded early in the process to ensure no options were missed. Two other team members with different disciplinary backgrounds each coded a subset of transcripts to reconcile discrepancies in the application/definition of the codes and ensure no codes were missing from the analysis. Dedoose software (SocioCultural
Research Consultants, LLC, Manhattan Beach, CA) was used to organize coded data. Once coded, team members analyzed transcripts to identify themes—groupings of one or more codes clustered around a discrete central concept—iteratively revising and generating sub-themes to establish conceptual clarity. Finally, we conducted member checks with five previously interviewed participants (one from each stakeholder group), presenting preliminary thematic results to assess and verify our understanding of interview content (Birt, Scott, Cavers, Campbell, & Walter, 2016). These participants supported and clarified the inductively-generated themes.

The scope of this analysis was specifically designed to examine stakeholder perceptions about features of primary care practice that influence the clinical management of people with dementia, caregiver needs, and acute care-seeking behavior. This follows the findings of the study’s initial analysis, which highlighted the perceived importance of taking a proactive approach to addressing caregiver needs as a means of preventing avoidable ED visits for persons with dementia (Jacobsohn et al., 2019).

Identification and synthesis of primary care features

Following the thematic analysis, all transcripts were again reviewed and open coded to identify the tangible aspects of primary care practice mentioned by participants as influencing caregiver decisions to seek emergency care. In a process consistent with Analytic Induction (Johnson, 2004; Pascale, 2010), research team members listed each identified feature, aggregated like items, synthesized the content of each aggregated set, and sorted the list into two groups: features leading to decisions to seek emergency care, and those that help prevent or reduce the need for ED use. Researchers then organized those features based on the previously identified themes.

Findings

Participants

Participant (n = 27) characteristics are described in Table 1. Our sample included: five primary care providers, five geriatric providers, four emergency medicine physicians, three community paramedics, five familial caregivers (one of whom was also a professional aging service provider), and five additional aging service providers (not including the

Table 1. Participant characteristics (N = 27).

<table>
<thead>
<tr>
<th></th>
<th>Familial caregivers (N = 5)</th>
<th>Primary care/geriatrics providers (N = 10)</th>
<th>Aging and/or dementia service providers (N = 6)</th>
<th>Emergency medicine physicians (N = 4)</th>
<th>Paramedics/emergency medical services (N = 3)</th>
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<td>60%</td>
<td>83%</td>
<td>0%</td>
<td>67%</td>
</tr>
<tr>
<td>Race (% non-Hispanic white)</td>
<td>83%</td>
<td>70%</td>
<td>100%</td>
<td>75%</td>
<td>100%</td>
</tr>
<tr>
<td>Clinics/organizational sites (#)</td>
<td>–</td>
<td>9</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

*aOne participant counted in this table as both a caregiver and aging service provider.*
Sixteen (59%) were female, with 22 (81%) identifying as non-Hispanic white. Average and median age was 46, ranging from 30 to 70 years old. Physicians/RNs represented 11 different clinical settings across 5 unaffiliated health systems in 2 states. This included five primary care clinics, four geriatric/memory specialty clinics, and two EDs. Paramedics represented two EMS organizations. Aging service providers were social workers from four different community organizations who worked directly with large numbers of persons with dementia and caregivers.

Primary care clinics represented had different types of organizational structures, including number/types of providers, staff, work team structure, in-house service offerings (social work, pharmacy, laboratory, etc.), appointment availability, scheduling, and clinic hours. Geographic locations covered contained both urban and rural areas (cities, small towns, and agricultural). These types of communities were evenly represented in the sample, based upon residence-types, clinical settings, and health/aging service coverage areas.

**Thematic analysis**

Our analysis of stakeholder perspectives identified 4 major themes describing features of primary care that influence acute care-seeking for older adults with dementia.

**Theme 1: Clinic and organizational features**

There was high congruence among stakeholder perceptions that operational factors related to primary care clinics’ structure had wide-ranging implications for health care providers’ abilities to deliver dementia-care services that address the needs of persons with dementia and caregivers.

**Clinic structure and access.** The inability of primary care clinics to provide acute care services to their patients living with dementia at the time when they are needed often contributes to ED utilization. The onset of new or escalating symptoms is unpredictable, rarely coinciding with regularly scheduled primary care appointments. Participants noted major practical constraints to primary care access for addressing these unanticipated problems, including limited after-hour and weekend availability (i.e., appointment availability, clinic hours). As one PCP said: “If you call your PCP and it’s after 4PM, the odds are they’re gonna say ‘go to urgent care or the ER... we don’t have any openings’” (PCP #16).

Participants also commented on problems caused by short visit lengths: “They have 10-15 minute visits. The family member wants to come in with a list and go through [it] and that’s not how the structure is... we are] operating in the constraints of the structure of that business” (Aging Service Provider #23).

Stakeholders also described logistical barriers to persons with dementia and caregivers’ use of clinic services. Transportation to appointments was cited as a particularly difficult issue for those with financial constraints or who live in rural areas:

> We will give people taxi vouchers or medical transport. It can be tough sometimes. That’s sometimes why follow up gets pushed back because it’s “I can’t get a ride” or “I’m gonna get a ride from somebody”... there’s a lot of people who you’re like “come in for a blood pressure check” and they can’t get in. They don’t have transport, they can’t afford a cab, they can’t take a bus. There’s a huge [problem], especially for people with more economic and social struggles. (PCP #24)
Care team roles and staffing. Even within the same healthcare organization, the primary care clinics represented had different role structures, which either facilitated or limited clinics’ abilities to address patient and/or caregiver needs. Participants who described a “care team” (professionals with varying patient-care roles and responsibilities) elaborated on how the makeup of the clinic staffing model influences caregivers’ proactive engagement in dementia-care decision making and abilities to find appropriate community-based resources:

I have a team I rely on with social workers and pharmacists... and a community-based nurse... they meet patients in their home, understand the home situation, the dynamics, and help them to manage those types of things. Then they bring in outside resources... They don’t need my expertise necessarily for medical management of stuff. It’s more social management that we really need to do and they’re the experts in doing that. (PCP #26)

Having some healthcare practitioner who has an understanding of the journey of dementia and the stages, doing work with a social worker connected to the community... and nurse practitioners who focus on the area of geriatrics. So you have a team of folks who hopefully... have connections to community resources. (Caregiver #14)

A few participants also discussed how working with a dedicated multi-disciplinary care team affects potential ED use by people living with dementia:

There could be a team of three or four people involved... that includes the primary care physician. He or she directs a couple of people that are gonna be the team for this person, and you are gonna call your team prior to calling the ambulance or taking them to the ED if you have issues. That way, a few people can learn about that person very intricately. (Paramedic #12)

Theme 2: Proactive approach to anticipate needs and avoid acute problems
Stakeholders suggested PCPs take a more proactive approach to dementia care to help manage or prevent acute illnesses and behavioral escalations that inevitably occur during disease progression.

Establishing goals of care and preparing for the future. Stakeholders discussed the necessity of advanced care planning for setting expectations and monitoring symptom progression. They strongly advocated for discussing goals of care, along with establishing a healthcare power of attorney and living will, soon after diagnosis before symptoms prevent people with dementia from participating in decision making and making their wishes known. PCPs in particular emphasized the importance of having well-documented actionable plans of care, accessible to providers throughout the healthcare system, as well as engaging family members to get everyone on board.

I think the other big thing beyond the behavioral symptoms is the idea of advance care planning and planning for the future. A huge part of that is education and counseling about some of the things you’ll expect to see in the coming six months to a year. (PCP #16)

The doctors I think—again the ones that I see that are the most successful—are the ones who have a plan, and then get that person connected to resources. And kind of give them some tips on potentially slowing down the progression. (Aging Service Provider #19)
PCPs highlighted how care planning, particularly anticipatory guidance about symptoms specific to that patient’s dementia type and stage, could reduce the need for acute unscheduled care. Having expectations for what might happen, and actionable plans to prevent these instances, greatly influences the decision to use primary care versus ED services. One described how fear of the unknown can lead persons with dementia and/or caregivers to seek ED care to relieve their uncertainty.

... If it hasn’t been discussed prior to an acute episode, a person is going to choose more care, more intervention, more transfers—more. Because there’s that fear aspect that it hasn’t been discussed. The not knowing just prompts people to “do”. The only way I can see a person reducing the “let’s just do it blindly and go forward” is to talk about ahead of time. (PCP #25)

Providing caregiver support, education, and resources to prevent crises. Caregiver support is essential to prevent crises that occur when caregivers do not know what to do. These often occur when there are sudden behavioral changes and/or the caregiver is struggling, e.g., the presentation of new symptoms or behavioral problems too difficult to manage at home. Participants identified dementia-related education as a critical way of bolstering caregivers’ knowledge, decision-making skills, and confidence handling situations which might otherwise lead to crises and/or possible ED use.

Part of it is just knowledge and training so they (caregivers) feel confident in what they’re doing for the person they’re caring for. Makes a huge difference if you don’t understand the dementia, if you don’t understand how to care for somebody or communicate with them. (Aging Service Provider #8)

As much communication as possible is probably the best way... for someone to be able to help the families so they have all the information. [There’s a] lack of information, lack of the type of advice or help that they could give a family in this situation... I think having education for caregivers, and having somebody tell you kind of what to expect—like they have the book “What to expect when you’re expecting”, almost like a guide of how to like navigate as people are having declines, to have more resources out there that are more real. (Caregiver #15)

Clinical stakeholders underscored how a caregiver’s lack of knowledge and skills handling common dementia-related situations could directly lead to acute care seeking. This includes education about which circumstances require ED care, which are better suited for primary care, and which could be handled in non-medical ways (e.g., behavioral strategies, accessing community resources).

Educate caregivers that these are not reasons to call the ambulance or reasons to take somebody to the hospital. It’s maybe having a point person for these people: Here’s what happened, here’s why you went to the emergency room, and here’s what you need to do in the future. (Paramedic #12)

They provide and they provide, they may not have any respite, and they provide till they’re exhausted and that they’re also maybe having health or mental health issues, and they end up coming to the Emergency Department as a last resort for help for the patient, which in turn is help for them. (Aging Service Provider #5)
**Provider–patient and provider–caregiver relationships.** Participants from multiple stakeholder groups discussed the importance of establishing and maintaining a trusting relationship between the PCP, patient, and caregiver. Such relationships facilitate identification of unmet needs and relevant community resources, willingness to communicate about emerging symptoms or problems, and shared decision making about care planning and treatment options. Within the context of a trusted provider–family relationship, PCPs have a greater opportunity to influence a person with dementia’s or caregiver’s willingness to seek help through community resources to better meet their needs.

*Being able to talk to that spouse individually...identifying that this is a really, really hard thing you’re doing caring for this loved one. What is it that you need that would be helpful for you? Sometimes just validating the fact that it’s hard so people don’t feel like they are on this island when they’re caring for a loved one with dementia. They feel like nobody really ever talks about this, no one else has been through this...really letting them talk and figuring out what they need, as well as educating them on what to expect for their loved one.* (PCP #2)

Other participants discussed how PCPs with long-term provider–patient relationships have historical knowledge of a patient’s medical situation that could be useful in determining whether ED services are warranted.

*When a family or a patient calls to be seen, staff may be more prone to say “no you should go to the emergency room” rather than offering them a clinic visit, just because of their age and overall comorbidities. But I’ve seen some instances where if I knew the patient well [I’d know] their acute-on-chronic confusion may be due to something that we can diagnose and treat in the clinic and keep them out of the ER. That’s better for everyone all around.* (PCP #27)

**Theme 3: Clinical skills & knowledge**

Participants expressed the need for PCPs and clinic staff to have greater dementia-related knowledge and skills that would bolster their ability to provide patient and family-centered care.

**Additional dementia-related training.** Stakeholders argued that, since primary care practices include older adults with dementia as part of their patient population, PCPs and clinic staff would benefit from having a solid grounding in both medical and psychosocial elements of dementia care. This includes training about different types of dementia, disease progression, treatment regimes, behavioral management techniques, communication skills, and providing clinical support to caregivers.

*This is truly a unique area of healthcare because it is different than just healthy aging...There’s a whole host of learning that would be required. It does put the burden on primary care physicians and nurse practitioners, that [has] to be a part of their professional understandings. That’s a real challenge. There is a gap there. There’s a great gap.* (Caregiver #14)

*I think one thing PCPs have pretty consistently needed help with is the behavioral symptoms, because there aren’t good pharmacologic treatments. So when they get a call from a caregiver*
that one of these patients is getting aggressive or violent, I don’t think a lot of PCPs would be comfortable managing that kind of acute behavioral symptom. (PCP #16)

I know that urinary tract infections are very common... that that can make behavioral symptoms and all kinds of things much worse. And that that might be all that it is. So I think caregivers would really benefit from knowing what kinds of things to look for. (Caregiver #18)

Some PCPs specifically described how additional training for all members of the clinical team would benefit their practices. Other health care providers advocating a team approach to dementia care cited their own lack of dementia training as a reason for working closely with social workers or nurses with more direct knowledge. Others expressed the desire for having up-to-date information about dementia-care best practices.

I think nursing training for dealing with patients with dementia would be really helpful. I don’t know that our primary care staff feels comfortable with all the issues that we’re talking about. And trying to help the family navigate some of those things too. (PCP #26)

**Ability to diagnose dementia and communicate that diagnosis.** Many stakeholders discussed the role of PCPs in diagnosing dementia. Some participants noted that a diagnosis can facilitate patient-centered primary care, which could minimize ED use. Others described how poorly communicated diagnosis and lack of follow-up lead to confusion or uncertainty about how to proceed.

It’s a really tough journey to navigate cuz it’s so new... I was just flying by the seat of my pants by myself trying to do it. Just hearing the diagnosis was really tough, y’know, they hand you this red folder of information and it’s overwhelming. You don’t wanna look at the folder because you can’t even process the fact that he has this disease... (Caregiver #15)

I think the diagnosis piece is lacking in primary care. I think there’s often a worry of labeling somebody with an incurable neurodegenerative disease, and so they tend to comment “Oh memory complaints, we’ll watch it.” They’re fairly advanced and they’re not aware that they actually have Alzheimer’s Disease or dementia...The actual diagnosis of Alzheimer’s disease is a challenge for primary care doctors. You see people who clearly have Alzheimer’s disease, who are fairly far along in the progression who’ve never heard the term. They don’t know they have it. It’s hard to do advanced care planning if you don’t know your diagnosis. (PCP #16)

PCPs in particular expressed contrasting views regarding the use of diagnostic tools during clinic visits. Some explained that multiple tests exist and have adequate functionality in screening patients for cognitive impairment, while others identified a lack of knowledge in which test to use or difficulty using them.

There’s no one test I can do. Often there’s a battery of things we tend to do to rule out reversible causes. What’s the cascade of testing that we should do when we suspect cognitive impairment or Alzheimer’s?... If there was a nice work up algorithm that we could use—that could be built into our EHR to help our folks out—that would be something worthwhile. (PCP #26)
I think from a diagnostic standpoint in primary care we’ll do the SLUMS testing or the MMSE, we’ll do the clock draw, the animal naming, the trail map... those take a considerable amount of time... and they’re helpful, but then there’s still that gray area... Truly the hardest part is to get a true diagnosis. (PCP #24)

Some doctors just kind of lightly say “Oh you’ve got a touch of dementia”. I think diagnosing this is a huge challenge for doctors, because what they communicate to their patients about what’s going on is so important... That’s kind of what doctors are left with sometimes, because there isn’t a whole lot that they can do... I see this huge gamut of different approaches to diagnosing and treating it. (Aging Service Provider #19)

Stakeholders also perceived that improving a PCP’s ability to provide or discuss a diagnosis may influence ED use by increasing awareness, decreasing uncertainty about the cause of new or changing symptoms, and providing patients and their caregivers opportunity to access dementia-related services that might help prevent the occurrence of acute problems. Some felt a PCP-confirmed diagnosis would be more likely to be accurately documented in the EHR, for potential use by urgent care or other providers when addressing acute problems that might result in ED referral.

Once my dad was diagnosed, there were no referrals to agencies that maybe could help, or people that really had the good dementia knowledge that could really start helping [us] get educated more on the effects of dementia on the person. (Caregiver & Aging Service Provider #17)

You’d see them going to the emergency room a lot, and then once the diagnosis was made, I think then the physicians working with that patient got a better handle on how to care for them. Until the diagnosis, they would go for various reasons. We always got them diagnosed and got them information so they’d know how to use it. (Aging Service Provider #23)

**Theme 4: Engaging services and resources**

Participants discussed how successfully caring for a complex condition like dementia involves taking an interprofessional approach that connects healthcare and community-based resources. Numerous stakeholders pointed to the role of primary care clinics in connecting older adults with dementia and caregivers to dementia-care services that meet their needs.

I would certainly spend more time with them to figure out what’s their living environment, what supports they have, especially when looking to the future as things progress. Do they have transportation needs? Food insecurity? Need help with chores, house-keeping, etc? Sometimes people are doing fine and they have kids a spouse that are high functioning and can do all of that for them, but if anything comes up or I have any concerns I would put in the referral to social work and she follows up very quickly with the family. (PCP #27)

I can’t help you in your home. I can’t help you navigate your neighborhood or go to community events, so I need an ally out in the community that can help continue and facilitate the plan that we’re creating. You have the healthcare provider, you have the patient and caregiver, and then you need to have some sort of community agency. (PCP #25)
I think would be great if they recognized a patient in need, that they would be able to connect them to a resource, like knowing that they live alone, or finding somebody who doesn’t have a good advocate and trying to get them an advocate. I think they do try that but it’s really hard. (Paramedic #5)

There was general agreement about the difficulties clinics face in making such connections, mainly arising from lack of knowledge about available community services. Many primary care clinics lack the capacity to assess which resources fit best based on the type and stage of dementia, as well as specific patient and/or caregiver needs.

We tell people to trust their doctors, talk to their doctors, yet so many doctors and specialists don’t know about the community agencies and what’s available to help people in their homes. (Aging Service Provider #8)

I think communication and coordination with community agencies is a big one. Just knowing what the resources are and having them readily available to refer to from our electronic health record system would be helpful... There’s a fair amount of resources... but it’s hard for us to know how to coordinate best with them. (PCP #10)

I just don’t know what the resources are necessarily... there’s so many... I mean you could go and look on a website, but how do you really know what’s the right program for what person? I don’t know how to figure it out. (PCP #24)

Factors preventing and promoting emergency services utilization

During their interviews, stakeholders frequently framed their healthcare experiences in terms of positive factors or challenges that need to be overcome to better address dementia-related needs. Positive experiences tended to result in the expression of features of primary care practice which prevented or minimized the need for emergency care-seeking (e.g., engaging in scenario planning/anticipatory guidance, having a designated team member with comprehensive knowledge of community dementia-care resources). Features of primary care that created the biggest challenges for stakeholders often increased the need for or promoted emergency-care seeking (e.g., lack of urgent appointment availability at primary care clinics, poor provider–caregiver communication, lack of caregiver education about disease progression and symptom management).

Stakeholder-identified factors were synthesized into 34 primary care features: 18 primary care features that prevent ED utilization and 16 features that promote caregiver decisions to seek emergency services (based upon the context of participants’ statements about these features in relationship to the themes). These are presented in Table 2, organized by the theme with which they most closely associated.

Discussion

This study examines stakeholder perceptions about features of primary care practice that influence dementia-related care and caregiver decision making in addressing acute problems, particularly as they promote or prevent the use of potentially avoidable ED services. These
<table>
<thead>
<tr>
<th>Theme</th>
<th>Features that prevent ED use</th>
<th>Features that promote ED use</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinic &amp; Organizational Features</strong></td>
<td>• Extended-length appointment slots</td>
<td>• Lack of care availability on evenings and weekends</td>
</tr>
<tr>
<td></td>
<td>• Caregiver-only appointments to identify/address needs</td>
<td>• Lack of urgent appointment availability</td>
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<tr>
<td></td>
<td>• Transportation vouchers (and help with use)</td>
<td>• Lack of transportation to clinic</td>
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<td></td>
<td>• Clinically integrated dementia care manager</td>
<td>• Phone triage prevents caregiver communication with providers</td>
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<tr>
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<td>• Clinically-integrated community nurse or social worker</td>
<td>• Clinical structure does not promote development and maintenance of relationships between providers/staff, patients with dementia, and caregivers</td>
</tr>
<tr>
<td></td>
<td>• Dementia-friendly physical environment</td>
<td>• Patient or caregiver difficulty using computer and/or phone/phone tree to communicate</td>
</tr>
<tr>
<td><strong>Proactive Approach to Avoid Acute Problems</strong></td>
<td>• Advanced care planning with persons with dementia and caregivers soon after diagnosis</td>
<td>• Lack of caregiver education about disease progression and symptoms specific to diagnosis</td>
</tr>
<tr>
<td></td>
<td>• Caregiver training on dealing with behavioral symptoms</td>
<td>• Lack of caregiver confidence about decision making</td>
</tr>
<tr>
<td></td>
<td>• Communicating importance of caregiver wellness (e.g., respite)</td>
<td>• Caregiver exhaustion and burnout; lack of coping strategies and respite options</td>
</tr>
<tr>
<td></td>
<td>• Scenario planning (anticipatory guidance, situational preparedness) for acute problems</td>
<td>• Caregiver fear and uncertainty</td>
</tr>
<tr>
<td></td>
<td>• Trusted provider-patient/provider-caregiver relationships</td>
<td>• Caregiver not knowing who to call under different circumstances</td>
</tr>
<tr>
<td><strong>Clinical Skills &amp; Knowledge</strong></td>
<td>• Timely and accurate diagnosis of dementia</td>
<td>• Lack of care team and caregiver knowledge about behavioral issues</td>
</tr>
<tr>
<td></td>
<td>• Professional development on dementia types, symptoms, and disease progression</td>
<td>• Poor skills for communicating with persons with dementia (across different diagnoses and disease stages)</td>
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<tr>
<td></td>
<td>• Additional training for clinic staff responding to phone calls</td>
<td>• Poor skills for communicating with familial caregivers (e.g., listening, trust-building, discussing difficult topics)</td>
</tr>
<tr>
<td><strong>Engaging Services &amp; Resources</strong></td>
<td>• Identifying specific resource-based needs of persons with dementia and caregivers, updated with changes over time</td>
<td>• Not providing information about educational, support, or logistical/instrumental resources</td>
</tr>
<tr>
<td></td>
<td>• Designated team member with comprehensive knowledge of community dementia-care/aging service resources</td>
<td>• Not understanding how persons with dementia and caregivers’ needs change as disease progresses</td>
</tr>
</tbody>
</table>

There is no parallel between features within each theme.
findings provide insight into the proactive and reactive aspects of treating persons with dementia in primary care clinics, further illuminating many barriers they face when seeking acute medical care (Alzheimer's Association & Centers for Disease Control and Prevention, 2018; Aminzadeh et al., 2012; Hinton et al., 2007; Koch & Iliffe, 2010; Low, McGrath, Swaffer, & Brodaty, 2018; Smith et al., 2018). By harnessing the personal experiences of healthcare providers, caregivers, and aging service providers, the findings of this study enable us to see these issues from multiple vantage points and develop a more holistic understanding of dementia care in primary practice.

The major emergent themes help elucidate gaps in primary care treatment of dementia, suggesting potential areas of future research and intervention development. Newer models of dementia care promote a proactive approach that largely involves providing caregiver support, education, resources, and advanced care planning (Callahan et al., 2014; Carter et al., 2018; Dening, Jones, & Sampson, 2011; Piers et al., 2018). This preventive framework, however, is partially reliant on PCPs’ skills, knowledge, and access to resources (Aminzadeh et al., 2012). We found that successful operationalization of this model of care is also contingent upon features like available appointment times, sufficient visit length, care team composition, adequate training, trusting provider–patient and provider–caregiver relationships, and strong partnerships with aging service providers.

The role of integrated interprofessional care teams in addressing stakeholder needs was a factor mentioned within the context of all four themes. Consistent with updated practice recommendations from the Alzheimer's Association and CDC (Alzheimer's Association & Centers for Disease Control and Prevention, 2018; Fazio, Pace, Flinner, & Kallmyer, 2018; Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018; Molony, Kolanowski, Van Haitsma, & Rooney, 2018; Nieuwboer, Richters, & van der Marck, 2017), this strategy clearly helps meet the needs of people with dementia and caregivers in terms of care management, access/referrals to appropriate resources, caregiver education and support, and improved communication with the clinic (Khanassov & Vedel, 2016; Lee et al., 2015; Wang et al., 2018). It also benefits healthcare providers by reducing the amount of knowledge physicians need about community resources, while increasing the dementia-care competencies of the clinical practice overall (Galvin, Valois, & Zweig, 2014; Moore et al., 2012). Having staff trained to assess persons with dementia and caregivers’ changing needs over the disease trajectory, connect families to available resources, and possibly conduct home visits, could reduce the (perceived or physiological) need to seek ED care.

Caregivers commented that relational and communication factors not only influenced their ability and willingness to seek acute illness care at their primary care clinic, but also their willingness to seek help from community service agencies. Participants expressed that the greater the trust between providers, patients, and caregivers, the more likely they were to access recommended sources of information and assistance (e.g., education, transportation). The interplay between the patient–provider–caregiver relationship and engagement of need-fulfilling community services is an important issue to address in developing integrated dementia-care practices.

Stakeholders also expressed the need for increased dementia-related training for PCPs and clinic team members, in addition to having easy access to information about (or referrals to) appropriate community services. These findings are supported by studies indicating that the knowledge, skills, and attitudes of persons with dementia, caregivers, and PCPs present major challenges in dementia care, and that connecting these patients and caregivers with community resources strongly influences primary care (Aminzadeh et al., 2012;
A.A. Jennings, Foley, McHugh, Browne, & Bradley, 2018; A. A. Jennings, Foley, Walsh, et al., 2018; Jensen & Inker, 2015; Ploeg et al., 2017). The capacity to identify and diagnose dementia remains a significant need for primary care clinics (Alzheimer’s Association & Centers for Disease Control and Prevention, 2018; Koch & Iliffe, 2010, 2011), one that our stakeholders suggested might affect uncertainty about the cause or progression of symptoms, as well as trust in a PCP’s ability to provide care. Collectively, the absence of these features may impede proactive approaches supporting people with dementia and caregivers, as well as promote more reactive models of care, increased reliance on pharmacological therapies, and ED utilization (Hinton et al., 2007; A. A. Jennings, Foley, Walsh, et al., 2018).

**Implications**

These findings help direct the development of future models of care, providing possible avenues for refining or combining existing interventions to improve primary care practice. Many features of primary care described by study participants are also possible targets for new interventions, designed with a specific goal of reducing avoidable ED visits. These interventions could include changes at the system, organization/clinic, or interpersonal levels of care, incorporating the stakeholder-derived factors presented in Table 2. Intervention development and implementation should employ ongoing stakeholder engagement strategies to ensure relevance and applicability to the targeted dementia population and clinical setting.

**Limitations**

The majority of study participants lived in Wisconsin, potentially obscuring regional differences in emergent themes based upon population characteristics or municipal support for social services. The study sample also lacked substantial cultural and ethnic diversity, possibly restricting the experiences described, limiting the resulting themes. Stakeholder sampling was designed to represent multiple dementia-care stakeholder groups (e.g., Fortinsky, 2001; Holmes & Adler, 2005; Jensen & Inker, 2015), rather than focusing only on a single perspective. In doing so, we did not obtain enough data from any one group (particularly caregivers) to make generalizations or comparisons between groups. Any hypothesis-generating findings from this study should be confirmed through larger representative national studies, including quantitative or mixed method approaches.

Our sample did not include two categories of stakeholders. The first is clinic administrators, whose perspectives might have contributed additional/different features. The second is persons living with dementia themselves. Prior studies have demonstrated that as persons with dementia start to have medical needs related to the disease (the point at which our study’s focus becomes relevant), they also begin perceive healthcare experiences/needs differently from their caregivers (Dean, Jenkinson, Wilcock, & Walker, 2014; Miranda-Castillo, Woods, & Orrell, 2013). Although it is methodologically justifiable to focus on caregiver perspectives when addressing medical decision making, as they increasingly act as surrogate decision-makers for their care recipients as dementia symptom severity increases (Fetherstonhaugh, McAuliffe, Shanley, Bauer, & Beattie, 2019; Karlawish, et al., 2002; Menne & Whitlatch, 2007; Miller, et al., 2016, 2017), the perspectives of early-stage patients with dementia are still absent from these findings.
Conclusion
Features of primary care practice influence the decisions of persons with dementia and familial caregivers regarding whether and when seek emergency care services, reflecting both proactive and reactive approaches to addressing dementia-care needs. Interventions for improving the quality of primary care for persons with dementia should consider incorporating stakeholder-identified factors, embedded within the 4 major themes, in ways that facilitate proactive family-centered dementia care and appropriately minimize caregiver decisions to utilize emergency services.

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