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Factors Influencing Emergency Care by Persons with Dementia: Stakeholder Perceptions and Unmet Needs

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Abstract

BACKGROUND/OBJECTIVES: People with dementia (PwD) frequently use emergency care services. To mitigate the disproportionately high rate of emergency care use by PwD, an understanding of contributing factors driving reliance on emergency care services, and identification of feasible alternatives is needed. This study aimed to identify clinician, caregiver, and service providers' views and experiences of unmet needs leading to emergency care use among community-dwelling PwD, and alternative ways of addressing these needs.

DESIGN: Qualitative, employing semi-structured interviews with clinicians, informal caregivers, and aging service providers.

SETTING: Wisconsin, United States.

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Author Contributions: All listed authors have contributed significantly to this paper, including study concept and design (MMH, AGB, NW, MNS), acquisition of subjects and data (MNS, MMH, AB), analysis and interpretation of data (GCJ, MMH, AGB, AB, NW, MNS), and preparation of manuscript (GCJ, MMH, AGB, AB, NW, MNS). The corresponding author affirms that he has listed everyone who contributed significantly to the work.

Impact Statement: We certify that this work is novel as these findings represent the first step to address unmet needs of dementia care stakeholders that lead to use of emergency care services by persons with dementia. The potential impact of this research is to inform innovative programs that either prevent the need for emergency care or deliver services through new primary care or community-based approaches.

Conflict of Interest: The authors have no conflicts of interest.

Sponsor's Role: No sponsor played a role in this paper's design, methods, subject recruitment, data collection, analysis, and preparation.

PARTICIPANTS: Informal caregivers of PwD (4), emergency medicine physicians (4), primary care physicians (5), geriatric healthcare providers (5), aging service providers (6), and community paramedics (3).

MEASUREMENTS: Demographic characteristics of participants and data from semi-structured interviews.

FINDINGS: Four major themes were identified from interviews: 1) system fragmentation influences emergency care use by PwD, 2) informational, decision-making, and social support needs influence emergency care use by PwD, 3) ED are not designed to optimally address PwD and caregiver needs, and 4) options to prevent and address emergency care needs of PwD.

CONCLUSION: Participants identified numerous system and individual-level unmet needs, and offered many recommendations to prevent or improve ED use by PwD. These novel findings, aggregating the perspectives of multiple dementia-care stakeholder groups, serve as the first step to developing interventions that prevent the need for emergency care or deliver tailored emergency care services to this vulnerable population through new approaches.

Keywords

Dementia; emergency department; caregiving; acute illness; primary care

INTRODUCTION

Alzheimer's Disease and related dementias affect one in ten adults age≥65 years.[1,2] It is estimated that in 2017, 6.1 million American adults had dementia, including mild cognitive impairment, and another 46.7 million had preclinical-stage dementia.[3] Persons with dementia (PwD) have complex medical and social needs that are often unpredictable due to substantial disease heterogeneity and changes with disease progression.[4] As frequent users of the healthcare system, PwD and their caregivers rely extensively on emergency department (ED) services to address acute medical needs and challenging behavioral symptoms, more so than other older adults.[1,5,6] ED use by PwD has been associated with higher rates of poor outcomes, including greater 30-day ED return rates; increased delirium, falls, behavioral problems, and mortality rates; and decreases in physical function.[6–9] Although the cause of these poor outcomes remains unknown, the overstimulating and unfamiliar environments, limited information available to providers, and lack of provider-patient relationships are seen as contributing factors.[8,10]

Because the majority of PwD presenting to the ED do not require hospitalization, researchers are working to develop alternative ways of providing services which better address PwD needs.[5,11–13] Health and service providers at the 2017/2018 National Research Summit on Dementia Care explicitly called for research to (1)"proactively support" PwD and to reduce the need for "reactive" medical services, (2)implement comprehensive models of care, and (3)validate the effects of different person-centered care practices on PwD's health and well-being.[14] Summit participants also called for additional research supporting informal caregivers' needs, as managing the complexities of dementia care, experiencing frustration, and coping with uncertainty about how to care for their loved one contribute to caregiver stress and burden.[15,16–18]

To inform the design of proactive, dementia-specific services to prevent or optimally deliver emergency care, we first must better understand how the needs and experiences of PwD's, informal caregivers, healthcare providers', and other stakeholders' influence ED use among community-dwelling PwD.[6,19] This study explores stakeholders' perspectives on the decisions and drivers influencing ED use, and suggestions for effectively addressing unmet needs.

METHODS

Study Design

This qualitative study, employing semi-structured in-depth interviews, is the initial phase of a program to develop interventions that prevent or lead to alternatives for emergency care for PwD. The University of Wisconsin-Madison Institutional Review Board approved the study. Study procedures and reporting are informed by the COnsolidated criteria for REporting Qualitative research criteria.[20]

Study Setting and Participants

We used purposive sampling strategies to identify individuals representing key stakeholder categories identified a priori: informal caregivers of PwD, emergency medicine physicians, primary care physicians (PCPs), geriatric healthcare providers (physician, nurse), aging service providers, and community paramedics (CP). We sought participants, particularly caregivers, who had experience caring for PwD at all stages of the disease so they would have sufficient perspective. PwD were not included because for this study, we were interested in hearing from care providers We recruited participants via email through referrals from community emergency medicine and geriatrics leaders. We used snowball sampling techniques to complete recruitment. Although we did not require caregivers to have experience taking their family member with dementia to an ED, all did. No individual approached refused to participate or dropped out after agreeing to participate, although two aging service providers did not respond to invitations.

Two members of the team (MMH, APB) with training in qualitative research conducted all 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: most often face-to-face in 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 themes were identified, based on joint assessment by study team members.[21] Participants received $50 for participating.

Data Collection

We developed and pilot-tested a semi-structured interview guide on staff members and emergency physicians not included in the study. Questions were informed by prior research and tailored to each stakeholder group (Appendix). Interviewers generated follow-up questions to clarify answers and pursue new lines of inquiry initiated by participant responses. The study team iteratively revised interview guide questions throughout the process to achieve study goals and expand upon emergent themes.[22] We made limited field notes during and after interviews.

Audio recordings of interviews were transcribed verbatim. We used Dedoose software (SocioCultural Research Consultants, Manhattan Beach, CA) to organize coded data. To ensure that comments remained confidential, all transcripts were de-identified.

We also collected basic demographic information so as to characterize the participants in the study.

Analysis

We used a Thematic Analysis framework[22–24] to code transcripts and identify meaningful patterns in the data. This iterative, reflexive, and systematic method is particularly suitable as it supports the development of both latent and semantic themes around multiple research questions—including participant experiences, influencing factors, and practices.

The study team coded transcripts concurrent with data collection, so the coding process could inform additional interview prompts. Two team members trained in qualitative interviewing and coding (MMH, APB) independently analyzed each transcript, systematically identifying key ideas and insights broadly related to the research questions. The codebook consisted of these inductively-derived codes, evolving over the course of the analysis to include additional or revised codes. Although each code was a discrete unit, a transcript segment (e.g., phrase) could be associated with multiple codes. After completing an initial analysis of all transcripts, the two coders revisited transcripts coded early in the process to ensure no final-codebook options were missed. Two additional trained researchers with different disciplinary backgrounds (MNS, GCJ) 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.

The team analyzed coded transcripts to identify themes—groupings of one or more codes clustered around a discrete inductively-derived central concept. Team members representing clinical and non-clinical disciplines reviewed proposed themes to determine how well they fit the data and encompassed important codes/excerpts. We revised themes to establish conceptual clarity. Finally, we conducted member checks with one previously-interviewed participant from each of the stakeholder groups, presenting preliminary thematic results to assess and verify our understanding of interview content.

FINDINGS

We interviewed 27 stakeholders about their dementia care needs, views, and experiences with emergency care use by PwD. Participants were informal caregivers of PwD (4), emergency medicine physicians (4), PCPs (5), geriatric healthcare providers (5), aging service providers (6), and CPs (3). Participants were, on average 46 years old (standard deviation=12), predominantly female (59%), non-Hispanic (100%), and white (22, 81%). Based on the interviews, we identified four overarching themes (Tables 1, 2, 3, and 4).

Theme 1: System Fragmentation Influences Emergency Care Use by PwD

Participants frequently described issues resulting from care fragmentation, including lack of communication between healthcare providers and integration with community services (Quote 1). Each source of care is necessary for patients and caregivers; yet participants from multiple stakeholder groups described them functioning in “silos”. Communication between healthcare providers was frequently described as inadequate, and coordination with social service agencies was often perceived as non-existent. For example, healthcare providers explained that many practices do not have direct access to aging service providers, and most PCPs do not know the available dementia-care resources (making it difficult to refer patients or coordinate with those services) (Quotes 2 & 3). Aging service providers described not having formal mechanisms through which to update healthcare providers about PwDs’ medical or psychosocial needs, or receive updates on acute health issues (Quotes 4 & 5). Caregivers suggested that if healthcare providers in different specialties could communicate regularly, they might better understand and address dementia-related medical problems as they occur (Quote 6).

Stakeholders emphasized other ways that this lack of coordination affects care quality and/or leads to emergency care use. For instance, emergency physicians do not always know why primary care providers have sent PwD to the ED, hindering their ability to provide quality care (particularly when PwD cannot clearly communicate it themselves) (Quote 7). Others reported instances when primary or specialty care providers did not put dementia diagnoses in patients’ electronic medical record, making it difficult for other healthcare providers (including ED physicians) to provide dementia-responsive care (Quote 8). This lack of coordination/communication often leaves PwD and caregivers in the position of having to supply healthcare and social services personnel with such information (Quote 9) increasing the potential for errors leading to acute medical situations.

Theme 2: Informational, Decision-Making, and Social Support Needs Influence Emergency Care Use by PwD

Participants across stakeholder groups described how individual-level needs, particularly relating to education/training, medical decision-making, and social support, contributed to crises resulting in ED use (Quotes 10–11). Caregivers’ lack of knowledge and uncertainty about what to do regarding specific symptoms, treatment options, and day-to-day management of medical conditions were identified as a major factor leading to emergency care use (Quotes 12–15). Caregivers expressed the need for information and help navigating difficult or new circumstances. However, many reported that their PCPs did not have the knowledge needed to help, and they did not know where else to go. Others felt uncomfortable asking for help because of social stigma, cultural/language barriers, or not wanting to “burden” their PCPs (Quote 16). These factors prevented some caregivers from contacting their regular providers about medical concerns until after they became acute, requiring them to seek ED services.

Similarly, some PCPs recognized that their need for additional dementia-care training and knowledge about community resources affected their ability to support PwD/families, as well as caregivers’ willingness to turn to them for dementia-related medical advice.

Providers also described the time-intensive nature of counseling families on managing a progressively-debilitating disease, preventing them from providing these services (Quote 17).

Multiple stakeholders also described how caregivers must constantly readjust their lives based upon patients' worsening symptoms, risking burnout and exhaustion (Quote 18). Participants discussed how the need for respite, particularly during behavioral crises, sometimes drives caregivers to seek emergency care (Quote 19).

Theme 3: EDs are not Designed to Optimally Address PwD and Caregiver Needs

The design and purpose of the ED may not be congruent with the needs of PwD and caregivers, or reasons why they seek emergency care. Participants discussed PwDs coming to the ED not because they were having a medical emergency, but because they were unable to access care otherwise (Quote 20). While medical issues have precedence in the ED, participants felt that social and environmental issues (e.g., living arrangements, familial support) also required attention to effectively address many PwD and caregiver needs (Quote 21). Due to emergency physicians' focus on solving acute medical problems, PwD presenting at the ED are often subject to tests and interventions, sometimes resulting in unwanted hospitalizations. Participants discussed how these medical interventions may be of little or no benefit to PwDs, and could even cause unnecessary harm (Quotes 20, 22–23).

ED care for PwD is particularly complicated because staff only encounter patients/caregivers after a crisis has arisen, lacking both the opportunity and means to address the root cause of the emergency (Quotes 24–25). This is difficult to do in an acute care environment where multiple staff members interact with each patient, often for a limited period of time. ED providers do not necessarily have knowledge of the patient's disease progression, social history, care plan, or appropriate dementia resources (Quote 26).

Theme 4: Options to Prevent and Address Emergency Care Needs of PwD

Participants shared ideas regarding alternatives to emergency care of PwD. Their suggestions focused on either preventing the crisis/illness using non-emergency services, or addressing it through new approaches to delivering care. Participants strongly supported prevention through upstream structural or process interventions (Quote 27). Central features of these intervention strategies included talking about advanced care planning and prevention, providing better education to caregivers, and improving information provision from caregivers to providers (Quotes 28–29). Participants were realistic, however, that despite improvement efforts, there will continue to be a need for high-quality emergency care.

Other approaches to care provision, circumventing ED care, focused on increased options for primary and urgent care. Some participants raised concerns with these options as not being feasible everywhere or by describing poor urgent care experiences (Quotes 30–31). When illnesses develop, participants preferred options that helped avoid transport to an ED or other facility. Such interventions included increasing home-based care options (Quotes 32–33) and providing resources to reduce caregiver uncertainty about whether a situation requires calling 911. Collaboration with other home-based healthcare providers, such as

CPs, was also viewed positively as a possible way of preventing ED use (Quote 34). Other intervention suggestions included having dementia care teams integrated into primary care clinics (including social workers) and the development of Geriatric EDs (Quotes 32, 35).

DISCUSSION

This study provides important insights into how care fragmentation, lack of accessible resources prior to crisis, and unmet patient/caregiver needs drive emergency care use for PwD. Many problems described by participants were potentially preventable or manageable, particularly when signs of medical illness or behavioral problems could have been addressed more effectively through early supports than reactive emergency care services.

This study incorporated multiple stakeholder voices not often included in dementia-care research to understand these unmet needs and challenges. Although there is a growing body of literature regarding PwD and caregiver needs, few studies have included the needs of healthcare and aging service providers.[25–28] These perspectives are important to understand and incorporate into the design of efficacious, sustainable interventions and coordinated systems of care. Another contribution of this study is the focus on care-related outcomes. Previous studies have focused on instrumental, psychological, educational, and social needs of PwD/caregivers. This study, however, looked at these needs in relation to subsequent healthcare use, which could function both a result of and contributing factor to previously measured outcomes. It is crucial to understand why PwD/caregivers seek emergency care before we can develop programs to prevent or optimally deliver these services.

The themes illustrate a strong desire for improvement across stakeholders. The range of needs described in Themes 1–2 are generally consistent with prior research on dementia care in healthcare settings. Needs commonly described include receiving relevant information about dementia management, disease progression, and symptoms, provider’s lack of knowledge or inability to provide useful community resources, and accessing sources of support for psychological distress.[4,26,28–35] Only one study described the need for PwD/caregivers to have information about whether or where to seek treatment for acute health or behavior-related problems—corroborating our stakeholders’ experiences about accessing emergency services out of “desperation” and lack of knowledge about other options.[36] Prior studies also identified needs for improved care coordination, communication and trust between providers/clinics and caregivers, and dementia-friendly ED environments.[13,35,37,38]

The calls for preventative/upstream approaches to acute care management for PwD, either using alternative care approaches or addressing the root cause of a problem before it becomes a crisis (Themes 3–4), have not been extensively addressed in earlier research. These interventions are particularly important for PwD given the challenges they face in travelling to and spending time in an ED. Our findings are consistent with Gagnon-Roy’s review[9], which identified crucial needs for additional research on preventing avoidable incidents leading to ED visits by PwD and creating evidence-based care strategies. Stakeholders in our study discussed how preventative/upstream measures are put in place only after an acute health incident has occurred (requiring emergency care), or too late in the course of dementia disease progression.

Addressing Needs

Participants offered wide-ranging ideas for changes, incorporating innovative best-practices for person-centered dementia-care, ideas similar to published interventions that have focused on improving care delivery through case management with a central case manager/care coordinator.[15,18,39,40] Although tasks vary, their role typically involves care planning, facilitating coordination across healthcare practices and social service agencies, helping families access needed resources, and providing disease-related information.[41–43] One issue addressed by employing case managers is that PwD/caregivers are hesitant to contact their primary care providers for assistance with dementia-related problems.[36,37] As substantiated by our participants, by the time patients/caregivers contact their PCP, the problem has reached a point of crisis.

While early evidence indicates that case manager-focused interventions are useful under certain conditions, another suggested approach involves adding a CP to the healthcare team. CPs can provide in-home, non-emergency services including care coordination and information gathering.[44–46] The existing 911 system structure allows CPs to be responsive quickly, particularly when clinics are closed, but this may adversely impact the 911 system or be cost prohibitive if the program is improperly implemented. Understanding their trusted role as paramedics, patients/families are also less hesitant to contact them with questions or for a problem.[47,48] If integrated fully into a healthcare team/system, CPs could function alongside or as an alternative to case managers, providing families with another resource to help with acute problems and preventative efforts. CP interventions have been employed with older adult populations as a method of reducing acute care services[49,50], but it's efficacy with PwD is unknown.

Limitations

Although enough participants were interviewed to reach informational redundancy, a smaller sub-sample represented each stakeholder group, preventing us from drawing comparisons across stakeholder groups. Our sample also did not have sufficient numbers to examine the experiences and needs of different cultural groups. While our study provides a rich description of the perceptions of care providers; we acknowledge that PwD were not included and recommend that future studies consider adding the perspectives of PwD. Finally, we would expect individuals receiving/providing care in organizations with vastly different dementia care management approaches might have experiences or suggestions not captured in this dataset.

CONCLUSION

Given the increasing prevalence of dementia and the high rates of ED use by PwD, it is critical to understand how the unmet needs of PwD, their caregivers, and other key stakeholders contribute. Our participants identified numerous system- and individual-level needs, identified that EDs are not designed to address PwD and their caregivers' needs, and offered many recommendations to prevent or improve ED use by PwD. These novel findings, aggregating multiple dementia-care perspectives specifically with regard to ED use, represent the represent the first step to addressing the unmet needs of stakeholders through designing innovative programs preventing the need for emergency care or offering additional tailored services to this vulnerable population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Quotations Illustrating Theme 1: System Fragmentation Influences Emergency Care Use by Persons with Dementia

#	Quote
1	"[My mother-in-law] had multiple ER visits and then sub-acute care, but they were at different facilities. [My husband] thought they all transferred all the records amongst themselves. When she would go to a new place, I'd say we gotta take these records and take 'em to the new place, and he would say "Why? Don't they all work together?"… I think a layperson thinks that healthcare providers, community-based providers, nursing homes—we all communicate. We don't." (aging service provider, ID 23)
2	"…I can't say I have any particularly close community partners with the AD community. …So I assume that they feel like this is the healthcare system doesn't reach out to them very often. So maybe we all sort of live in our own little bubbles. I'm sure that there's a lost opportunity because of that lack of contact." (PCP, ID 4)
3	"Communication and coordination with the 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… in the moment when things are happening, we don't necessarily have that available. There's a fair amount of resources… But I also feel like they're not coordinated as well…Or at least if they are coordinated, it's hard for us (clinicians) to know how to coordinate best with them." (PCP, ID 10)
4	"I think again it goes to…the systems level communication, between professionals. Especially when it comes to discharge services, who's doing what, what's needed in the home, is there enough planning time? I know I frequently got calls from hospitals …saying 'Your client's getting discharged today'. I didn't even know they were in the hospital! And trying to piece that together is a lot of work." (aging service provider, ID 8)
5	I mean there's more than just me involved with somebody. It's helpful for me to know the other professional, whatever their profession is, because if I'm doing something with a client, and then I find out they're doing the same thing, well that's a lot of time wasted… I think collaboration, especially with people with dementia, is really important. Whether it's doctors, or family, or whoever. (aging service provider, ID 20)
6	"Communication between geriatrician and the PCP is so vital and important… having like all the different docs be on the same page, and be communicating with the patient. And for the geriatrician to be able to send a report to the PCP to say 'Hey here's where your patient's at', so they're educated when they come in for other aches and pains (and know) what they might be experiencing could be related to the dementia. (caregiver, ID 15)
7	"It always helps to understand the kind of motivations that get people sent to the emergency room. I think if I could understand why this PCP is sending half of his patients to the Emergency Department without seeing them, or if he's seeing them, how often, or whether he seeing them for follow-up when I recommended it." (ED Physician, ID 1)
8	"I think a particular problem is when we see patients, especially with early-stage dementia, we don't realize that they have any Alzheimer's-type dementia, and we just kind of assume that people can carry out this complex series of (discharge) tasks that if you think about it is almost designed to be the type of thing that someone with early type Alzheimer's is going to struggle with." (ED Physician, ID 3)
9	"There are times when I think that there hasn't been an understanding, and the doctor is seeing one thing, and might not have the information on the whole picture. I fill that gap." (caregiver, ID 14)

Table 2.

Quotations Illustrating Theme 2: Informational, Decision-Making, and Social Support Needs Influence Emergency Care Use by PwD

#	Quote
10	“In particular, we know that when a crisis moment happens is when a person will go to the emergency room…they go because something has gone so wrong that the caregiver can no longer handle the situation, whether it’s the caregiver is burned out or that the situation is actually dangerous.” (geriatric healthcare provider, ID 25)
11	“…one group of people that I see come in through the ED to us a lot…just have a mismatch between the supports they have and what they need. It doesn’t mean that [their] needs are that high or that they are that hard to meet, it’s just that the type of support them have is not appropriate. (geriatric healthcare provider, ID 11)
12	“Two times he fell…it was basically dehydration. Only I didn’t know what dehydration looked like, I wondered if he had a stroke…I mean it was terrifying. Then I called the doctor’s office and they said ‘Oh it was just probably dehydration, you don’t have to worry’. I said I think I’d like to come in today just to look at this…” (caregiver, ID 22)
13	“…So for caregivers again, they may feel unsure, or lack confidence in terms of how they’re managing the patient…” (ED physician, ID 2)
14	“I probably could have dealt with it or taken him myself, but I did call 911. So the EMTs came and I was really glad I had because it was something I didn’t really know what was going on, and he was acting a little strange.” (caregiver, ID 18)
15	“You know it’s like how do you figure out how to help the caregiver prevent the escalations that are leading to unnecessary ER visits, especially for agitation because that’s I’m sure a lot of what they see. It’s the mental status changes, how can they intervene from a behavioral standpoint to prevent that from happening, and that’s a huge time consuming education.” (PCP, ID 24)
16	“I think because of stigma that caregivers and patients tend not to want to reach out for help, because it’s viewed as a personal matter that they should be able to take care of themselves.” (aging service provider, ID 23)
17	“A huge part of Alzheimer’s Disease is education and counseling about what are some of the things you’re gonna expect to see in the coming six months to a year…how do you think about your other co-morbidities in the setting of a neurodegenerative disease. I don’t think those conversations happen in the typical primary care office. It’s not that they don’t want to have them, it’s that I don’t think they necessarily have the tools to have the conversations? And they certainly don’t have the time. (geriatric healthcare provider, ID 16)
18	“The caregiver’s just like ‘I’m done for the day, and I need to go out and go for a walk and somebody come and stay with her or him’…their fallback is ‘I’m just going to call the ambulance and I’m just going to go to the emergency room’…because they don’t know what else to do. And then the emergency room resets them and sends them back home… You get that three or four hours of break in the ER, where you don’t have to deal with it.” (community paramedic, ID 12)
19	“…They need respite…those caregivers need help and sometimes bringing Mom to the emergency department is just their call for help. (ED physician, ID 1)

Table 3.

Quotations Illustrating Theme 3: EDs are not designed to Optimally Address Patients with Dementia and Caregiver Needs

#	Quote
20	"…when something is going poorly, having nothing in place to get help in the home is why the ER has become such as common last refuge for these patients. I think they feel like there's nowhere else they can go. And they end up in the ER, and then they're on the conveyor belt of healthcare and all of a sudden they're in the in the hospital. Nobody wants that but I don't think there's alternatives to care where we can respond to some of these issues at home. I think needs are not being met for these community patients." (geriatric healthcare provider, ID 16)
21	"….I do think there's definitely an association with healthcare utilization, both in terms of ED visits and admissions, based on the living circumstance. I think… people with increased social isolation are at higher risk for readmission and things like that." (ED physician, ID 21)
22	"…we're very focused on identifying and removing life-threatening diseases and we use a lot of diagnostic testing and other resources to do that. And we tend to do fairly aggressive work-ups in the Emergency Department. [We] could perform a more focused work-up, or a work-up that doesn't include so many resources…saving patients from harm to themselves by undergoing testing that they don't need." (ED physician, ID 3)
23	"They need to have someone who recognizes that they're different from their baseline… The challenge [is that] it's difficult to get a good history, and even the exam can be somewhat unreliable. It ends up being bigger work-ups…so they'll get CAT scans of their heads, and they'll get X rays and blood tests that they may or may not need. But a lot of that's secondary to the fact that they're difficult historians. (ED physician, ID 2).
24	"I'm not a geriatrician I'm not an internist in a clinic or anything like that. Those are the kind of needs that those people see every day. Is their hypertension being addressed, I don't know? I see them as an endpoint when they get to the emergency room. Right? And so (I don't know) what their actual medical needs are. It's hard for me to say…I see them as their problem when they get into the emergency room, rather than before they get to the emergency room." (ED physician, ID 1)
25	"There was a time when my dad ended up having a fever on a weekend, and he was just burning up. So I took him to urgent care and they tried to take blood, and all of his veins collapsed… So they rushed him in the ambulance to the hospital… it was a really traumatic experience for my dad in the ER because they (were) checking his chest, and they started to do a lumbar puncture…and my poor dad, who couldn't communicate is staring at me like 'What the hell are you letting people do to me'." (caregiver, ID 15)
26	"The biggest complaint about the ER for any patient is how many times I [they] had to tell the same thing… Especially when you're older and you're not feeling good. I'm telling and who is this person, and who is this person, I mean whenever I do the interview after a discharge that's the number one complaint. And feeling kind of a less intimate (relationship). They just want the one doctor. They want it the way it was. (community paramedic, ID 5)

Table 4.

Quotations Illustrating Theme 4: Options to Prevent and Address Acute Care Needs of Persons with Dementia

#	Quote
27	"So the absolute key for these patients is upstream interventions. And I think we have some upstream interventions for some supportive care but I don't know if we have a medical upstream intervention. Our upstream intervention has been "Call 911"…And I think that's hard…human nature is we kind of try to do all we can, until it kind of hits crisis mode." (geriatric healthcare provider, ID 16)
28	"So maybe education of 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 you need to do in the future."(community paramedic, ID 12)
29	"The other thing is you'll see a person come in, the family member sends them in, but the person has no insight, so the doc [PCP] takes what information they're given, and acts upon it. But they didn't know that the patient got lost two days earlier. So the patient tells them what they think- like what they know, so the doc doesn't always get what they need to do." (aging service provider, ID 23)
30	"We have really great primary care [where I practice] even though it's busy…there's very likely a nurse practitioner or physician assistant available; our patients don't have to go to the ER generally because…they can't get an appointment with us, and then there's also the [blinded] urgent care as well, so I don't see…patients in my practice setting doing that a lot. But I mean I know of it happening, I know of it happening…[in] practice settings where I've worked." (PCP, ID 10)
31	"…when it comes to the evenings or the weekends…you're probably better off starting at urgent care [rather than calling the PCP]." (geriatric healthcare provider, ID 17)
32	"…there's a geriatric ED…[or] seeing more of these patients cared for in the community, in their own homes, I think assuming that there wasn't something specific from the hospital they needed, is generally a good thing." (ED physician, ID 21)
33	"It's been wonderful to be able to tap into [hospice] because…they came right away, and showed us how to dress him, and showed us like what to do…I think having the people come to the house where he's sitting in his comfortable chair, and it's a much more quiet environment, I think makes a huge difference." (caregiver, ID 15)
34	"There may be 911 calls that happen because of a fall, and they don't necessarily automatically have to be taken to the ED. An assessment can happen where the patient and the paramedic are able to determine that it was simply a mechanical fall, and see what we can do to help prevent that from happening again. They have coordination with a clinician if they have questions to verify and make sure that they don't need to be seen urgently or have a medical assessment…if a community paramedic is going to visit them, then they can relay to us what's going on, we might be able to work together to help prevent them from having to go to the ED." (PCP, ID 10)
35	"I think at least having some knowledge of what kinds of services are available and what the possibilities are might be helpful…we have social workers that know this stuff…. So I can say y'know Mrs Smith over there she needs help…But other emergency departments don't have that luxury. I think it would be helpful to have some overview of what kind of services would be available." (ED physician, ID 1)