Tailoring Research Recruitment for Acute Care Settings
Recommendations from People with Dementia and their Caregivers

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Background: There is a pressing need to increase enrollment and representation in Alzheimer's disease and related dementia (ADRD) research. Current recruitment approaches focus largely on clinic and community settings, with minimal engagement of acute care environments despite their broad use across diverse populations. The objectives of this study were to examine views, preferences, and recommendations regarding acute care–based ADRD research recruitment among persons with dementia and their caregivers.

Methods: The authors conducted semistructured interviews with recently hospitalized persons with dementia (N = 3) and family caregivers (N = 28). Interviews were analyzed using thematic analysis.

Findings: All participants endorsed acute care as an appropriate time for recruitment into ADRD research studies and identified important elements of an appropriately tailored recruitment approach and an interpersonally effective research staff. Participants emphasized that this approach should consider the acute care context with respect to participant situation, uncertainty, and timing. Participant suggestions informed the design of a 5-step process to guide ADRD research recruitment in the context of acute care.

Discussion: Findings provide valuable insights from people with dementia and their caregivers regarding opportunities for research engagement surrounding acute care and can inform expanded recruitment in these settings.

Key Words: Alzheimer's and dementia, recruitment, enrollment, acute care

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The World Health Organization's Global Plan to address the societal challenges presented by Alzheimer's disease and related dementias (ADRD) emphasizes the need for comprehensive action toward improving research participation to ensure continued progress toward identification of effective prevention, treatment, and care.[1,2] Along with the need to increase enrollment in ADRD research, there is growing recognition of the need to address the long-standing under-inclusion of under-represented populations in ADRD research, particularly given their disproportionately higher disease risk and poorer outcomes. Efforts to bolster representation in ADRD research may necessitate expanding settings through which ADRD research recruitment takes place, in addition to careful consideration of the accessibility and inclusivity of recruitment approaches used by garnering broader input from prospective participants. Most ADRD research recruitment takes place through the clinic and community-based networks.[3,4] Yet reliance on these settings may inadvertently exclude individuals who are not connected to outpatient care, are socially isolated, or otherwise lack connections to the formal community networks typically leveraged in recruitment efforts (eg, churches or faith networks and community centers), which may disproportionately impact individuals from under-represented backgrounds.[5–7]

Research suggests that some under-represented populations, including racial/ethnic minority, immigrant, and socioeconomically disadvantaged populations, are less likely to have access to care and are more likely to use acute care settings for routine health needs.[8,9] Acute care settings, including emergency and inpatient settings, are commonly engaged to facilitate research recruitment in other fields such as emergency and palliative medicine.[10,11] However, they have been largely overlooked as potential additional settings to facilitate ADRD research recruitment. Such settings are particularly relevant to ADRD populations, as persons with ADRD are frequent utilizers of acute care compared with counterparts, having nearly 2 times as many hospital stays as their counterparts without ADRD.[12–14] Reasons for limited ADRD research recruitment in acute care settings are poorly understood but may be due in part to the assumption that acute care is an undesirable time for research recruitment. Input from people with ADRD and their caregivers can inform our understanding of the potential utility of acute care environments for facilitating ADRD research recruitment. Understanding caregivers' perspectives is particularly important as they frequently serve as proxy decision makers for research participation decisions and are often prospective participants themselves as approximately half are biological children who may be eligible for recruitment into preclinical trials.[15,16]

Little is known regarding perceptions of prospective participants regarding ADRD research recruitment in the specific context of acute care, limiting potential decisions around setting-specific recruitment approaches and strategies. Key

informant interviews are an effective strategy for eliciting perspectives regarding experiences, preferences, and values that may shape participant priorities and needs specific to research recruitment through acute care settings. Thus, the objective of this study was to elicit and examine the views, preferences, and recommendations of patients with ADRD and their caregivers regarding acute care–based recruitment for ADRD research through semistructured interviews.

METHODS

Design

This study used a prospective descriptive qualitative design with semistructured individual and dyadic interviews. Major research questions were established a priori and informed interview questions and development of a semistructured interview guide. Interviews were designed to (1) elicit participants' perspectives in response to invitations to participate in an ADRD study (recruitment practices) in the acute care context; (2) identify factors participants weighed when deciding to participate; (3) probe perceived readiness, barriers, and facilitators; and (4) garner input on steps researchers should take when recruiting people with ADRD and their caregivers in acute care environments.

Study Setting and Participants

All study procedures were reviewed and approved by an Institutional Review Board before the commencement of study procedures. Potential participants were recruited from the emergency department (ED), medical, and surgical units of an urban academic medical center through referrals from ED and transitional care staff. These specific services (ED and transitional care) were selected as they provide broad coverage of units across the institution. Staff on these services identified patients with a prehospitalization diagnosis of ADRD through routine review of patients' electronic health records to screen for a prehospitalization diagnosis of ADRD. Before referring potentially eligible patients to the study team, clinical staff reviewed the electronic health records to determine the presence of a primary caregiver and/or legally authorized representative, and whether legally authorized representatives were activated (ie, the presence of an activated power of attorney indicating patient lacks medical decisional capacity). In the absence of a legally authorized representative and other indicators of a lack of capacity to consent to research participation, staff on these services determined initial interest on behalf of both the primary caregiver and person with ADRD in learning more about the study from the research team. If a legally authorized representative was present, initial contact was made only with the legally authorized representative and/or other eligible caregivers. If interested in learning more about the research study, staff facilitated hand-off to the research team by providing either the patient's room number if they desired an in-person conversation and/or potential participant's preferred contact information for follow-up at a later time. Research staff followed-up in a timely manner to explain the study details, including the purpose, requirements, risks and benefits, and elective nature, and to answer any questions.

Research staff performed a brief eligibility screen for persons interested in the study. Eligibility criteria for ADRD participants included: (1) the presence of a prehospitalization diagnosis of ADRD, (2) ability to participate in an interview in English, and (3) demonstrated decisional capacity through established procedures designed for acute care dementia recruitment.[17] Caregiver participants were eligible if they (1) provided care to a hospitalized patient with a prehospitalization diagnosis of dementia and (2) provided direct or supportive care to the person with ADRD at least monthly, and (3) could participate in an interview in English. For situations where both the person with ADRD and caregiver were eligible to participate, they could participate in the interview as a dyad or individually. Participants received a US$50 honorarium upon completion of the study.

Data Collection

If eligible, before data collection, research staff completed informed consent with all study participants. During the informed consent procedure, research staff reviewed an information sheet including all pertinent study details and provided ample time for participants to ask questions. Participants provided verbal consent before participation, with informed consent waived by the Institutional Review Board to minimize the risk of loss of confidentiality to participants. The research team had no prior relationship with participants. Data collection took place over 8 months in 1-hour long interviews, and thematic saturation was reached after 25 participants had been interviewed. A further 6 participants were interviewed to confirm data saturation across major findings. All interview materials were reviewed by a Community Advisory Board to ensure clarity. Throughout data collection, the study team met to discuss emerging themes that were recorded using a memoing procedure.

Data Analysis

All transcripts were analyzed in their entirety using a thematic analysis approach, which is an iterative, systematic, and inductive method for reliably discerning common themes across research participants.[18] To develop a standardized data-driven coding framework (Supplementary Material 1, Supplemental Digital Content 1, http://links.lww.com/WAD/A307), all study team members reviewed a subset of transcripts to determine relevant codes and met to iteratively derive the coding framework. This coding framework was then trialed on a separate subset of transcripts, after which study team members again convened to discuss the ease of applying the coding framework and whether any interview data were insufficiently or accurately represented by the coding framework, with revisions applied yielding a standardized coding framework. The standardized coding framework was then applied across transcripts through line-by-line coding in NVivo 12.[19] Twelve transcripts were reviewed independently by at least 2 coders to enable assessment of intercoder agreement and identify the need for retraining or clarification of codes. Inter-rater reliability for the coding of these 12 transcripts was high with an average percent agreement of 98.9% ($\kappa = 0.832$). Disagreements were resolved in discussion with the entire coding team. Given the high agreement among coders, all subsequent transcripts were coded individually.

Codes were reviewed to identify patterns and similarities across interviews to identify salient themes.[18] The study team did not utilize a preconceived theoretical framework but instead relied on participant data to guide analysis. To enhance rigor, after saturation was achieved resultant findings and recommended acute care recruitment guidance were brought to an additional 6 participants in a visual and video format to provide an opportunity for endorsement, refutation, or expansion of suggested recruitment steps. Referencing Lincoln and Guba's concept of

qualitative trustworthiness, our analysis procedures demonstrated credibility and dependability through the study team's engagement in critical discussion throughout each step of the analysis to reduce researcher-biased interpretation of the data.[20]

RESULTS

Participants

Collectively, 95 potentially eligible patients were referred to the study team by hospital staff. Of these 95 referrals, 30 were not able to be contacted by the study team as an activated legally authorized representative was not present during the hospital stay. The remaining participants were not enrolled for the following reasons: 26 because of challenges making phone contact, 3 were discharged before the first contact by the research team, and 8 declined to participate. Twenty-eight interviews were conducted with 31 participants, including 3 people with dementia and 28 caregivers. Three interviews were dyadic. Twenty-eight participants were white, 1 African American, 1 Hispanic, and 1 Native American. Participant demographic characteristics are detailed in Table 1.

All participants felt an acute illness care episode was an appropriate time for recruitment into ADRD studies, given specific considerations for timing and the nature of invitations, and preferred abilities among research staff facilitating invitations. Four participants also requested to complete the study interview while within the acute illness care setting; this was not a preference or option for all participants primarily because of timing with discharge and space constraints. No major differences were found between the perspectives of caregiver and person with ADRD participants.

TABLE 1. Participant Characteristics

Characteristics	n (%)
Age (y)	
20-29	2 (6.45)
30-39	1 (3.23)
40-49	1 (3.23)
50-59	4 (12.90)
60-69	7 (22.58)
70-79	10 (35.71)
80-89	1 (3.23)
90-100	1 (3.23)
Not reported	4 (12.90)
Sex	
Female	20 (64.52)
Male	8 (25.81)
Not reported	3 (9.68)
Ethnicity	
African American	1 (3.23)
Hispanic	1 (3.23)
Native American	1 (3.23)
White	28 (90.32)
Education level	
High school diploma or equivalent	2 (6.45)
Technical school, vocational training, community college	3 (9.68)
Some college	1 (3.23)
4-Year college	9 (29.03)
Post college	12 (38.71)
Not reported	4 (12.90)
Employment status	
Full-time	7 (22.58)
Part-time	3 (9.68)
Not working	1 (3.23)
Retired	16 (51.61)
Interview type	
Dyadic	3 (10.71)
Individual	25 (89.29)
Participant type	
Person with dementia	3 (9.67)
Caregiver	28 (90.32)
Caregiver relation to care recipient	
Spouse	14 (45.16)
Child	10 (32.26)
Other relative	3 (9.68)
Friend	3 (9.68)
Person with dementia only (no caregiver present)	1 (3.23)
Care recipient living conditions	
Person with dementia lives with caregiver in their home	17 (54.84)
Person with dementia lives in assisted living facility	14 (45.16)
Participant population density	
Rural	2 (6.45)
Urban cluster	8 (25.81)
Urban	5 (16.13)
Not reported	16 (51.61)

Thematic Findings

Research Staff Attributes and Skills May be the Most Important Consideration for Acute Care Recruitment

Participants described specific researcher attributes and skills as critical to successful recruitment, with these descriptions far outweighing any other considerations shared by participants. Participants preferred staff to be "very kind, very thoughtful," "very personable," "knowledgeable," and "attuned to [the person's] feelings," and to have "a very accepting personality." Participants described preferring researchers who approach them with respect and free of pressure, recommending staff who were "not pushy," "not forceful," and "sweet, no high pressure or anything." Participants emphasized needing researchers to communicate clearly, directly, and authentically as they explain key study details in plain language but without "talking down" to them. Participants wanted research staff to be genuine and skilled in adapting communication to each unique person and circumstance. Altogether, participants described these preferred researcher attributes and skills as enabling researcher-participant relationships to foster quickly, thus facilitating their interest and subsequent engagement. In some instances, the perceived impact of these relationships extended to the institution at large. One participant who said they generally "detest" research but linked positive relationships with previous researchers to the larger institution and subsequent participation: "but I did it because I had an unusually positive experience with [hospital name]." Participants also spontaneously shared that they appreciated having a conversation with the research staff. The importance of conversation and relationship carried beyond the recruitment phase; several caregivers and participants with dementia preferred to have the same researcher who approached them to also facilitate their participation in research, both for consistency and as a way to build a relationship.

Acute Care Recruitment Approach Must Consider Situation, Periods of Uncertainty, and Preferred Timing

Participants stated that the acute care situation (eg, reason for hospitalization), periods of uncertainty (eg, discharge planning), and timing (eg, early afternoon) were important considerations for the recruitment approach.

Participants wanted researchers to be cognizant of the person with ADRD's reason for hospitalization and to avoid the earlier periods of the hospital stay when they are more likely to receive more intensive care. Participants also suggested avoiding periods that require complex decision making by the care network (eg, determining discharge location later in the stay): "*… don't burden people when they are trying to make their decisions. They are making the decision to admit to the hospital or hospice or go back to where she's been or move her right away and if it's life and death.*" Participants also described the "revolving door" phenomenon that occurs during hospitalization wherein multiple staff enter the room and the feelings of confusion and disruption that can ensue, presenting important timing considerations for research staff: "*I couldn't really tell who were researchers and who were doctors I was mainly focused on you know the caregivers wanted to know who the primary caregiver were. I didn't really distinguish, there might have been researchers there.*" Caregiver participants also noted the potential for changes in mood and cognition that can occur during hospitalization, describing later in the day as a more common time of increased confusion.

Though participants raised these points for consideration, none felt these factors were prohibitive for research recruitment. Rather, many noted enthusiasm about *any* ADRD specific research opportunity and also emphasized there was a lot of "down time" across the acute care stay, from the emergency room to inpatient unit: "*it worked quite nicely because it was taking us a while to get us discharged and the research recruiter met with me during this time so that was really no problem.*" Specifically, several participants identified early afternoons as potentially opportune times for recruitment, to avoid the busyness of the morning when rounds often occur and the fatigue and confusion that can accompany the evening. Participants also suggested allowing potential participants the opportunity to weigh in on timing (eg, asking "Is this an okay time to talk?"), following-up through email or phone call, or scheduling another time to come back. Finally, participants emphasized their need for time to make decisions, especially given the importance of shared or distributed decision-making patterns across the caregiving network.

Resultant Recruitment Steps Condoned by Caregiver Participants and Community Members

Collectively, participant preferences and recommendations regarding tailored recruitment approaches in the acute care setting shaped 5 participant-endorsed recruitment steps (Fig. 1): (1) determining the timing for approach, (2) clear introduction as a research staff, (3) building rapport, (4) understanding situation and preferences, (5) if interested, clearly and succinctly describing the study.

In step 1, participants and community members alike felt the research staff must determine appropriate times to approach the hospitalized person with dementia and/or their caregiver about a research study. Specifically, participants felt the research staff should understand the trajectory of their hospital stay and relevant medical or social information (eg, whether the person with dementia has an activated power of attorney), which could be obtained through chart review or by speaking to the referring clinician. However, participants did not feel strongly that research staff be

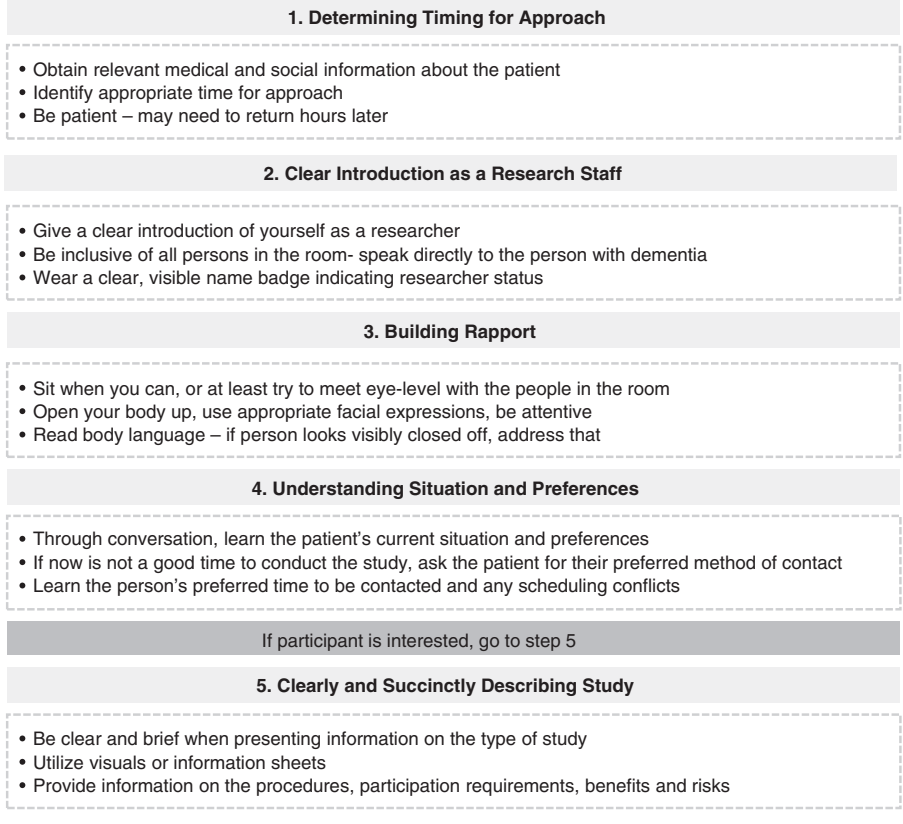

FIGURE 1. Participant endorsed steps for acute care–based Alzheimer's disease and related dementia research recruitment.

introduced by the hospital staff, as long as the research staff clearly introduced themselves. As such, step 2 for research staff involves a clear introduction inclusive of *all* persons in the room, ensuring their conversation includes the person with dementia and not solely caregivers or family. Critical aspects of the introduction include name, role as a researcher, and affiliation to help differentiate researchers from clinical staff.

Participants and community members alike shared the importance of relationship building, leading to step 3 of building rapport, which facilitates many participants' desire for interaction during a hospital stay and provides research staff with valuable time to complete step 4 of understanding prospective participants' unique situation and preferences. For example, through conversation, the research staff may learn whether the participant is feeling fatigued or if the participant would prefer that a family member be present.

After building rapport and understanding, the research staff can determine whether to proceed to describe the study or if a different avenue for follow-up is necessary (step 5). Several participants preferred the inclusion of a brief eligibility screen before an in-depth explanation of procedures to avoid wasting potential participants' time if they do not meet the inclusion criteria. Participants emphasized the need for clarity and brevity, desiring information on the type of study, procedures involved, participation requirements (when, where, and duration), and benefits and risks. Participants shared study safety, reasonable requirements for duration and location, and appropriate incentives could maximize potential participation. Participants expressed the importance of having this information on a handout, brochure, or flyer to refer back to at a later time, particularly given the quantity of information provided during a hospital stay. After hearing about the research, participants wanted time to make decisions and to be asked for their preferred methods for follow-up (eg, phone call, mail, or email correspondence).

Across Steps, Participants Emphasized Role of Person With Dementia and Caregiver Network in Making Decisions to Participate in Research

Caregiver participants identified the inclusion of the person with dementia as important during initial recruitment and decision making. Some caregivers emphasized the agency of the person with dementia to hold a meaningful conversation beyond early disease stages, though they might require support with specific aspects of the conversation research: "*she [person with dementia] can have conversations very easily … I like being there at times to advocate for her and once in a while make a little correction.*" Altogether, caregiver participants emphasized the need to provide persons with dementia with adequate time and space to maximize their potential for involvement. Of note, caregivers felt that inclusion of the person with dementia was important even in situations where only the caregiver is eligible as a proxy informant, as they felt the study inherently "involved" disclosure about information with the care recipient, and overwhelmingly sought their input in decision making.

General Perspectives on Research May Play a Role in More Specific Acute Care Recruitment Interactions

Though interviews were specific to acute care recruitment, all participants readily shared a variety of pre-existing perspectives on research, often relating these to their motivations to participate in research generally (Table 2). Although some participants drew from prior participation in research, most had no prior research experience. Although most participants felt that research is beneficial to society, central to finding treatment and cures, and personally helpful and rewarding; some responses highlighted negative, cautious, or indifferent attitudes toward research participation. For example, knowledge of research misconduct and suspicion about research methods or goals had a significant impact on multiple participants' views of research. One participant specifically mentioned the Henrietta Lacks case and said, "*I do know that sometimes research can be not carried out appropriately. And sometimes if it's sponsored by certain pharmaceutical companies, then maybe it's, you know, I think you have to be ethical.*"

Participants also identified a range of personal motivations for participating in research studies (Table 2). Several participants explained their motivation to participate in research as stemming from a kind of reciprocal altruism, or the belief that participating in research would provide both researchers and participants with benefits. The specific benefits participants hoped to reap from participating in the research included contributing (even in a small way) to a cure, helping to advance knowledge in general, and learning the ultimate results of the study. Ten participants explicitly expressed an interest in learning the results of the study they participate in, stating that it "sure would be nice" and "I would love to know the results."

Other common motivators included access to resources and support and access to treatment. Specific to resources and support, participants expressed a desire for information and tools on dementia, a way to express their difficulties, and an opportunity to meet similar people. Specific to treatment, participants frequently described their motivation as a desire for personal prognosis improvement and obtaining access to treatment for themselves or their care recipient. Participants often struggled to readily differentiate between clinical and research staff, blurring treatment and research and complicating decision making and interpretation of motivational factors.

DISCUSSION

Emergent research suggests that multifaceted recruitment mechanisms, incorporating a variety of recruitment settings and media-based strategies, may bolster study accessibility, enrollment, and representativeness.[21,22] Findings from this study provide tangible insights from participants regarding steps researchers can take to expand recruitment efforts into acute care environments specifically, which may help to broaden accessibility by making another recruitment channel available. In this study, participants with dementia and caregiver participants endorsed acute care settings as an appropriate venue for ADRD research recruitment, though they also communicated clear preferences for *how and when* research invitations are presented in this setting. Namely, participants emphasize the critical need for a relationship; a thoughtful, respectful, and genuine interpersonal approach; and consideration of their unique situation and timing requirements throughout the research recruitment process. Findings also highlight the importance of person-centered recruitment efforts adapted to the needs of participants with dementia and their caregivers and suggest that approaching a potential research participant should be viewed as the beginning of the cultivation of a researcher-participant relationship.

TABLE 2. Major Thematic Findings in Participant Recommendations for Acute Care Recruitment Into Alzheimer's Disease and Related Dementias Research Studies

Example Dimensions of Thematic Findings	Illustrative Quotes
Research staff attributes and skills may be the most important consideration for acute care recruitment	
Positive personal attributes among research staff desired	"He [the recruiter] is just a relaxed kind of guy. Had kind of a caring feeling about it, not 'oh-we need to do this'." "They have just always been very respectful in terms of asking me to participate"
Adaptive communication skills critical for recruitment	"You have to, when you're dealing with these people, you have to back off and figure out how they respond to things before you dig into things. So how do they respond? What is their personality like?" "Try to be attuned to their [potential participants'] feelings" "I don't like to be put on the spot by someone coming in and saying will you do this."
Detailed and clear communication needed central to the recruitment approach and description of the study	"You need a little more detail. Describing what it is before you describe the goal. Make sure they understand what it means. Because if they don't you could have problems down the road." "Come and being straightforward, saying who they are, what they are there for and stuff is an important thing." "How many days a week it involves, how much time it would be every day if it was every day, and would it interfere with my already busy schedule."
Importance of having a conversation and building a relationship with successful recruitment	"I think an actual person you know over the phone or an actual conversation is more effective for me." "When I talked to this gal that I got these phone calls from [the research interviewer] and that was nice and I liked that cause I could sit there and talk to her for hours-hour and a half."
Acute care recruitment approach must consider situation, periods of uncertainty, and preferred timing	
Reason for and context of a person's acute care situation including related acute care work processes are important considerations	"She was there for something very life-threatening … I probably wouldn't want the person to contact me about doing a study at that particular moment in time." "I couldn't really tell who were researchers and who were doctors I was mainly focused on you know the caregivers wanted to know who the primary caregiver were. I didn't really distinguish, there might have been researchers there." "If I just found out some horrible health news and somebody came to talk about a research study to participate I would be like not so much."
Periods of uncertainty may pose challenges for recruitment and decisions to participate	"When she first arrived. She had been there quite a while when… you gotta get them settled in and get a sense of how stable they are." "Don't burden people when they are trying to make their decisions. They are making the decision to admit to the hospital or hospice or go back to where she's been or move her right away and if it's life and death."
Recruiters must consider a person with dementia's patterns in cognition and preferred timing	"I don't know, all I can say is the afternoons are better to make it comfortable and has somebody that has a very pleasant personality." "You have to make sure that … the person's not medicated in a way that's going to make them drowsy."
Across steps, participants emphasized the role of a person with dementia and caregiver network in making decisions to participate in research	
Inclusion of persons with dementia in conversations about research participation viewed as important, though perspectives on *how* differed	*Caregiver participant describing the person with dementia's ability to participate in conversations and research:* "I mean she [the person with dementia] can have those conversations very easily. She doesn't advocate well for herself but she can speak up very well." "I'd be too worried to leave him [the person with dementia] alone … I don't know maybe a researcher should know the caregiver feels like they have to be there all the time you know that they are well cared for." "When it's introduced to her [the person with dementia] I would want to be there. I wouldn't need to be there for the study because then I know that she knows what's going on."

TABLE 2. (*continued*)

Example Dimensions of Thematic Findings	Illustrative Quotes
General perspectives on research may play a role in more specific acute care recruitment interactions	
Varying familiarity with and perspectives on research may influence acute care recruitment preferences	"I love research! My husband is in research so it was our life for many years" "Well, I mean, you've probably read the Henrietta Lacks books and things like that where I think if it's not handled appropriately, and I think we're doing so much better, but I do know that sometimes research can be not carried out appropriately. And sometimes if it's sponsored by certain pharmaceutical companies then maybe it's, you know, I think you have to be ethical. So I do obviously think about the ethics of things."
Shared personal motivations for research participation may influence acute care research recruitment preferences	*Reciprocal altruism:* "I guess our motivation all along has been strong in maybe they can find something that will help us and maybe we could do something that will help them." *Altruism, related to personal connection to disease*: "I feel that anything I can do to help down the road, is well worth, my time, and energy, and well with the Alzheimer's thing, it's very close to our family, I feel very strongly about that." *Gaining access to resources or support: "*Well a lot of the challenges I met while being a caregiver was not knowing how to be a caregiver and all the sudden you're thrown into it […]. And I think it would've been really helpful to have been in a study and have someone on the inside saying now you do this." *Monetary compensation:* "Like because some people are just like no I don't want anything to do with it. But then if that's something like, or say hey it's a paid research study going on would that be something you are interested in learning about?" *Generating a sense of worth:* "'you have this diagnosis where you can help us so much by sharing what's going on with you and just a lot more affirmation that his contribution is really valuable. […].' And to have a diagnosis like that and yet still be valued as a contributing member of society I think is really important even if they don't remember it the next day."

Prior research has emphasized linking attitudes about ADRD research to motivation to participate.[23–26] Previous research has found that motivation to participate depends considerably on the participants' attitudes toward research, with specific concerns regarding the potential harm, time consumption, or futility of research participation contributing to poorer attitudes toward research.[26–30] Results of the present study suggest that decisions to participate in ADRD research may involve more factors than extant attitudes alone. In agreement with research that has identified institutional factors,[7] this study found interpersonal, situational, and study-specific factors play a vital role, suggesting that a host of factors beyond extant attitudes might be salient and should be further investigated. Consistent with our findings, in an interview study of participants of Alzheimer's disease-related clinical trials and their decisions to engage in research, Bardach et al[27] found that an understanding of the importance of research and motivation to help others in the future were acknowledged as motivators for participating in ADRD research and that positive relationships with research personnel encouraged continued involvement. Rather than treat barriers and facilitators as isolated factors, investigators might better conceptualize them as interdependent pieces of a holistic recruitment context. Furthermore, these results suggest training procedures in the 5 recruitment steps and practice of nonverbal communication may be useful in making future research recruitment more effective, regardless of extant attitudes.

Most caregiver participants wanted the person with dementia to be included in the research as much as possible. Such supported or surrogate decision making has been described as the product of multiple agents such as family members, friends, associates, or public attorneys.[25,31,32] This broader inclusion was very meaningful to participants as they relied upon the inclusion of the person with dementia to shape decisions. This preference may have implications for recruitment in other environments and can inform growing efforts to identify improved methods for inclusion of people with dementia in research.

It is important to note that the research recruitment steps participants endorsed have the potential to apply regardless of the acute illness care context. Reinforcing positive research staff attributes, considering context and timing of recruitment approach, and including the personal network of the person with dementia in the research recruitment process are all factors that can be considered universal to research recruitment involving individuals with dementia. These endorsed steps therefore may have utility for research recruitment in other contexts.

This study has a number of limitations. Most participants were college/post bachelor educated, white, English-speaking, and retired. Not only do the sample limitations limit the generalizability of the study, but they may have further biased the results of the study toward more ethnocentric perspectives. In addition, persons holding these identities may have varying historical and current reference points with research that may shape their research preferences. Additional research in nonacademic contexts and with more diverse populations is a critical next step to address facilitators and barriers to research participation

surrounding acute care and to confirm the utility of the development recruitment steps with more diverse populations.

In addition, this study recruited participants from a single acute care setting, which may limit the transferability of the findings. The study recruitment site was an academic, not-for-profit hospital, which could mean participants had greater exposure to academic research and third-party observations during their hospital visits that may bias the study results. In addition, the fact that the participants interviewed had already agreed to be recruited through the context of acute care possibly biased results toward the acceptability of acute care research recruitment, and data were not collected from the persons who declined to participate or were lost to attrition on their perceived acceptability of the recruitment mechanism. It is important to note that declining to participate or otherwise may not equate to negative views on the recruitment mechanism as there are multifaceted reasons that surround an individuals' choice to participate. Moreover, the current study did not attempt to determine participant views on acute care recruitment versus other settings of recruitment, as many of the interview questions were facilitated by reflecting on the participants' proximal lived experiences with acute care–based dementia research recruitment. Future research that aims to compare different recruitment settings or modes must be cognizant of the challenge of determining participant views on unfamiliar experiences.

Some participants in the present study felt comfortable expressing hesitancy or disinclination toward research participation in general, which indicates the kind of research being conducted might be a factor affecting willingness to participate and should be investigated in future research. There is also a need for the prospective data collection on the effectiveness of research recruitment, including a measure of attitudes that capture relationship development in addition to attitudes among caregivers regarding participation in research.[4] Although other measures exist (notably the Research Attitudes Questionnaire),[33] such tools do not reflect the degree and quality of researcher-participant relationship building.

Finally, though we found no major differences in attitudes toward research recruitment during acute illness care episodes between participants with ADRD and caregivers, this may be because of the fact that we did not include comparative analysis between participant types as a study objective, which drove unequal recruitment of each participant group and the use of the same interview questions for both participants with ADRD and caregivers. Future research is needed to better delineate the perspectives of people with ADRD on research recruitment in acute illness care settings, and whether their views differ from caregivers who may experience the hospitalization from a different viewpoint and role. Along these lines, the underlying health conditions that led people with ADRD to an acute illness care setting were not systemically collected, limiting our ability to determine whether health status played a role in participants' views on research recruitment. This information was instead shared voluntarily during interviews.

Settings and methods for ADRD research recruitment will undoubtedly need to be expanded to increase enrollment and diversity of research participants. These tailored recruitment strategies for acute care settings are the first derived solely from a person with dementia and caregiver input and can serve to inform future efforts to expand ADRD research recruitment into these environments.

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