

Original Research Articles

Facilitators and Barriers to Engaging Families of Persons with Dementia in Research within Geriatric Clinics in Nigeria: Perspectives from Families

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Introduction

Despite the central role of families in dementia caregiving, limited research has examined what shapes their willingness and ability to participate in dementia research.

Objective(s)

This study explored the relational, cultural, and structural factors influencing families' engagement in research within a psychogeriatric clinic in Nigeria.

Methods

We employed a narrative qualitative approach, recruiting 12 caregivers of people living with dementia from a Nigerian psychogeriatric clinic. Participants engaged in semi-structured interviews at their homes, providing rich reflections on their lived experiences, expectations, and perceptions of participating in dementia-related research. Data were subjected to thematic analysis to capture the nuanced meanings families attach to research participation within their sociocultural contexts.

Results

Families described several facilitators to research participation, including access to healthcare, opportunities to gain dementia-related knowledge, trust in healthcare professionals, and material or financial support. Conversely, significant barriers included lengthy assessments, emotional exhaustion, limited communication of research findings, and uncertainty about the purpose of research. Therapeutic misconception such as the expectation that participation would directly improve the health of their relative influenced recruitment and retention. Families emphasized the importance of involving them and the person with dementia in every stage of study planning to enhance trust, relevance, ethical responsiveness, and cultural sensitivity.

Discussion

Aligning research procedures with participant expectations, enhancing transparency and communication, addressing therapeutic misconception and undue inducement, and integrating families into the research process may strengthen recruitment, retention, and the broader social impact of dementia research in African settings.

INTRODUCTION

The inclusion of older adults in clinical research is critical for understanding the burden and progression of age-related conditions such as dementia.¹⁻³ Despite this importance, older adults remain underrepresented in such studies, limiting the generalizability of findings and the

effectiveness of interventions targeting this population.^{2,4} Traditional barriers, including frailty, cognitive decline, and comorbidity, have long made participation challenging.⁵ However, recent evidence suggests that the challenges are more complex, reflecting sociocultural, ethical, and structural factors.^{6,7}

Plain Language Summary

a. What is already known about this subject?

Families provide most dementia care in Africa, yet they are often underrepresented in research planning and decision-making. What is already known is that dementia research in many African countries depends heavily on family participation, but trust, stigma, limited dementia knowledge, transport burden, time demands, and unclear communication can affect recruitment and retention.

b. What are the new findings/contributions?

This study contributes new insights by showing how families in a Nigerian geriatric clinic understood and experienced dementia research. It highlights that families were motivated by access to care, new knowledge, incentives, and hope for better support. However, long assessments, limited feedback, and unclear boundaries between research and treatment created barriers. A key finding is the role of therapeutic misconception, where some families believed participation would directly improve the patient's health. The study also shows that involving older adults and caregivers in designing research may strengthen trust, improve relevance, and reduce misunderstanding.

c. How might our results change the direction of clinical/care practices?

These findings have potential to influence clinical and general dementia care by encouraging more transparent communication, routine feedback to families, culturally sensitive engagement, and stronger caregiver education. Clinics and researchers may need to treat families as partners in care and knowledge production.

Stigma surrounding dementia is a major impediment to participation, particularly in African and other global contexts. Cultural myths, religious beliefs, and fear of labelling often discourage older adults from engaging in studies investigating cognitive health.^{8,9} Family gatekeeping, in which caregivers or relatives control whether an older adult participates, can further limit access even when individuals are willing.^{10,11} Additionally, obtaining informed consent in dementia research is ethically and logistically complex. Declining cognitive capacity poses challenges for respecting autonomy, particularly in genomic studies, where participants and families may be concerned about how genetic data will be used, stored, or shared in contexts with low regulatory oversight or historical mistrust.^{4,12-14}

Although the importance of including older adults in dementia research is widely acknowledged, there is limited understanding of factors that either facilitate or inhibit participation of families in dementia research in Nigeria.¹⁵ Addressing this gap is essential to designing inclusive recruitment strategies, fostering trust, improving participation rates, and ensuring that older Nigerians are adequately represented in research to inform dementia care.

OBJECTIVES

This study sought to answer: What factors influence older adults' willingness to participate in dementia research? What concerns and motivations shape their engagement? Insights aim to inform strategies to improve recruitment, retention, and community-centered approaches in dementia research in African region.

METHODS

Study design: Employing a rigorous narrative qualitative methodology, this study interrogated the lived experiences of older adults (aged 60 years and above) diagnosed with dementia, alongside their primary care partners, within the context of dementia research conducted in Southwest Nigeria from January to September 2024. The narrative approach, rooted in the epistemological premise that human beings construct meaning through the articulation of lived stories, was deliberately chosen to transcend the limitations of fragmented participant responses. This methodology facilitated a nuanced exploration of the interplay between individual, communal, and environmental factors, thereby illuminating the multifaceted ways in which participants interpret and negotiate their realities.¹⁶ Through in-depth, semi-structured interviews, participants were encouraged to recount their experiences in their own idiom, fostering the emergence of rich, contextually embedded narratives. This approach not only privileged the authenticity of participants' voices but also enabled the identification of salient themes and patterns that underpin engagement with dementia research. By situating participants' accounts within broader socio-cultural and ethical frameworks, the narrative qualitative design yielded an expansive and analytically robust understanding of research participation, positioning the study at the vanguard of qualitative inquiry in this domain.

Study setting: The study took place at the memory clinic of Chief Tony Annenih Geriatric Centre (CTAGC), University College Hospital (UCH), and various communities in Ibadan, Nigeria. Ibadan's traditional family structures and strong community networks, alongside urbanization, shape dementia care for older adults. CTAGC provided access to multidisciplinary geriatric services and ongoing research, while the community sites offered insights into everyday caregiving practices outside of the clinical setting. Integrating clinical and community settings enabled a comprehensive view of dementia care, engagement, retention, and ethical issues in a low-resource context.

Development of Interview Guide: The interview guide was developed by the research team based on the study objectives and relevant literature on dementia care and caregiver/family engagement. It consisted of open-ended questions and prompts designed to explore participants' experiences, perceptions, barriers, caregiving roles, and recommendations related to dementia research and care. To ensure cultural appropriateness and clarity, the guide underwent expert review by qualitative researchers within the team. It was further validated *via* a pilot test with participants whose characteristics paralleled the target study population.

Ethical considerations: This study received ethical approval from the Joint Ethics Committee of the Oyo State Ministry of Health Ethical Review Board (Approval number AD 13/479/44509B), following a full-board review to ensure compliance with national and international standards for research involving human participants, particularly adults with cognitive impairment. Approval was granted after the Committee evaluated the study's protocol, participant recruitment procedures, data protection plan, and the safeguards proposed for engaging persons with dementia. Given that the study involved persons with dementia who may experience varying levels of cognitive impairment a tiered and participant-centered consent process was implemented in line with ethical best practices for research in dementia populations.

Throughout the study, participants and their family members were informed that participation was entirely voluntary and that they retained the right to withdraw at any time without consequence. Modest financial incentives were provided to participants to offset transportation expenses and compensate for the time associated with their participation in the study. All interviews were conducted with sensitivity to participants' cognitive needs using simple language, a slow pace, and regular check-ins to confirm continuing comfort and willingness. Strict measures were implemented to protect the confidentiality of participants' data. All information collected was anonymized, securely stored, and accessible only to authorized research team members. No identifying information was included in transcripts, reports, or publications. The research team adhered to established data protection protocols to ensure privacy and integrity of the data throughout the research process.

Participants and Procedure: We purposefully recruited twelve family units comprising people living with dementia and their primary caregivers from Southwest Nigeria between January and September 2024. Primary caregivers qualified for inclusion if they had assumed the principal caregiving role for at least six months. Even though researchers hold a position of authority, the risk of coercion was minimised by ensuring that participation was voluntary and clearly presented as optional in the recruitment materials and consent process. Participants were recruited through the World Brain Health Survey platform, typically via online invitations, public appeals, or partner organisations; this self-selection mechanism may enhance motivation but can also tilt the sample towards those who are

more interested in brain health or have reliable internet access.

A purposive sampling approach, informed by the principle of maximum variation, ensured the cohort reflected diversity in gender, socioeconomic status, caregiving arrangements, and previous research experience. Recruitment continued until thematic sufficiency was achieved defined as the point at which further interviews ceased to yield novel perspectives regarding participation and engagement in dementia research. Prior to enrolment, all participants received comprehensive information about the study's purpose, procedures, and their right to decline or withdraw without consequence. Interviews were conducted with careful attention to participants' comfort and well-being. If a participant showed signs of distress or discomfort at any point, the interview was paused or discontinued. There were no participant dropouts after recruitment and consent. However, the study only captured the perspectives of individuals who agreed to participate. It is possible that individuals who declined participation or were unavailable may have experienced different or more significant barriers, which may not be fully reflected in the findings.

Data Collection: The research team consisted of clinicians and public health researchers with extensive experience working with older adults and community stakeholders, which facilitated rapport building during interviews. Interviews were conducted by a multidisciplinary team consisting of OE, a psychiatrist, CO, FA, and CE (public health researchers). All members shared extensive experience in qualitative research and community-based health studies in Nigeria. Data collection was carried out using a Key Informant Interview Guide (Supplemental Material), designed to elicit nuanced accounts of participants' experiences, perceptions, and engagement with dementia research. All interviews were conducted in participants' homes at a time convenient to them. Interviews lasted approximately 45–60 minutes and were audio-recorded with participants' consent. The interviewers did not have pre-existing relationships with participants. Key questions that were explored can be found in the Key Informant Interview Guide (Supplemental Materials). Interviews were transcribed verbatim, allowing for both systematic and in-depth exploration of salient topics. This rigorous recruitment and data collection strategy was intended to ensure a breadth of perspectives, yielding a comprehensive understanding of factors influencing participation, retention, and ethical practice in dementia research within resource-limited settings.

Data Analysis: Data was analyzed using a narrative analysis approach, selected for its capacity to illuminate how older adults living with dementia and their caregivers construct, communicate, and interpret their own engagement in the research process within specific social and cultural contexts. The analytic process was iterative, reflexive, and inductively grounded in the data as guided by Braun and Clark.¹⁷ The research team reflected on their professional backgrounds and how these may have shaped their interpretation of participants' narratives. OO is trained in medical social work, FA is a public health professional, TO

is a public health researcher, and OE is a psychiatrist and geriatrician with a special interest in older adults living with memory conditions. These professional experiences may have influenced how the team understood and interpreted the participants' perspectives. Transcripts were first read repeatedly by the analytic team (F.A., T.O., and O.E.) to achieve a holistic understanding of each participant's narrative and its contextual underpinnings. To mitigate interpretive bias and strengthen methodological rigor, this study integrated a systematic back-translation procedure within a broader reflexive research framework. Throughout data collection and analysis, the research team engaged in ongoing reflexive dialogue and adhered closely to a structured interview guide to maintain consistency across interviews. All interviews conducted in Yoruba were initially translated into English by trained bilingual research assistants with contextual familiarity. To ensure semantic and conceptual equivalence, an independent bilingual translator subsequently performed a back-translation of selected transcripts from English into Yoruba without reference to the original versions. This iterative verification process enabled the identification of subtle discrepancies in meaning, nuance, or cultural expression. Any inconsistencies were critically examined by the research team and resolved through collaborative deliberation, thereby preserving the integrity of participants' accounts and enhancing the credibility and trustworthiness of the analytic process prior to formal coding and interpretation. Data were analyzed manually. Interview transcripts were read and re-read to ensure familiarization with the data. Initial codes were generated by hand through systematic line-by-line coding. Codes were then grouped into categories and refined into overarching themes using a thematic analysis approach. Data management supported using Microsoft Word to organize and track codes. Open coding was employed to generate initial descriptive codes, which were then systematically refined through team meetings. Codes were evaluated and developed based on their frequency across cases, direct relevance to the research questions, and the depth of meaning expressed by participants. This process ensured that analytic decisions prioritized both the salience and richness of emergent concepts. As analysis progressed, codes were organized into hierarchical nodes, and themes were generated by examining connections, recurring patterns, and meaningful variations across narratives ([Table 1](#)).

Key analytic decisions, such as criteria for code refinement and theme selection, were explicitly documented and discussed during regular team meetings. Disagreements in interpretation were resolved through collaborative review of transcripts and field notes, ensuring analytic rigor and transparency. For example, when differing perspectives emerged regarding whether caregiver burden should be conceptualized as a distinct theme or as part of a broader "experience of participation" theme, the team revisited field notes and participant quotations. This re-examination illuminated nuanced dimensions of burden, ultimately leading to the articulation of a more comprehensive and contextually grounded theme.

Several challenges were encountered during analysis, including the potential for researcher bias given the interpretive nature of narrative analysis and the team's prior involvement in dementia research. To address these limitations, member checking was conducted with eight participants, who reviewed selected codes and themes for resonance and accuracy. Their feedback prompted further refinement of analytic categories and supported the trustworthiness of findings. Ongoing reflexivity was maintained through analytic memo writing and open discussion of positionality within the research team. This collaborative and reflexive approach ensured that diverse interpretations were considered, enriching the analytic process and enhancing the credibility and reproducibility of study findings.

RESULTS

A total of twelve dyads (two older adults living with dementia and 10 caregivers) were recruited and interviewed. Their ages ranged from 39 to 83 years, with varying educational backgrounds (three participants had a secondary educational level, and nine had a tertiary educational level). Seven participants were female, and five were male, with two widowed and 10 married. Additionally, the participants had varying occupations (seven were retired and unemployed, two were employed in civil service, two were self-employed, and one didn't state her occupation).

OVERVIEW OF FINDINGS

The findings reveal that families' engagement in dementia research in Nigeria is shaped by a complex interplay of hope, caregiving realities, structural gaps in care, and expectations of relational accountability. Participants viewed research participation as something valuable when it produced practical, emotional, and social benefits within everyday life. Knowledge gained through participation was interpreted as actionable and communal, helping families recognize symptoms, improve caregiving practices, and educate others within the community. Research participation was also associated with hope for health improvement, restoration of memory, and recovery of personhood. For most of the families, their participation in research was symbolically intertwined with care, treatment, and social recognition. Participants also perceived research participation as a potential tool for reducing stigma, particularly in communities where dementia symptoms are sometimes interpreted through supernatural or moral frameworks such as witchcraft. Engagement in research was complicated by burdens associated with prolonged assessments, emotional fatigue, and lack of post-study feedback. Participants interpreted the absence of feedback as a failure of reciprocity, suggesting that ethical research extends beyond consent to include communication, acknowledgment, and relational care.

Table 1. Summary of Themes

Theme	Sub-theme
Perceived Benefits	Knowledge acquisition as practical and social value
	Research as hope for health improvement and restored personhood
	Stigma reduction and re-socialization of dementia
	Community engagement and extension into everyday care
Experienced Burdens	Prolonged assessment as strain, fatigue, and ethical discomfort
	Absence of post-study feedback as broken reciprocity
Motivators for Engagement	Financial and material incentives
	Desire for treatment and practical support
	Basic care and hospitality during participation
Recommendations	Improved transparency and meaningful dissemination
	Reciprocity, pre-engagement, and relationship building

1. PERCEIVED BENEFITS

Participants described research participation as potentially beneficial at multiple levels: personal, relational, and communal. These perceived benefits were interpreted through its practical relevance to everyday caregiving, symptom recognition, health improvement, and social awareness. In this sense, the perceived value of research was grounded in lived usefulness.

1A. KNOWLEDGE ACQUISITION AS PRACTICAL AND SOCIAL VALUE

A prominent way participants constructed the benefits of research was through the language of learning. Research participation was understood as a means of acquiring knowledge about dementia, particularly its symptoms, management, and treatment. Yet participants' accounts suggest that this knowledge was appreciated because it could be converted into care practices, shared with others, and mobilized within the community.

As PT1 stated:

“My research knowledge is when one is acquiring knowledge about dementia, its symptoms, management and treatment, which can be useful to the community if it has to do with medical research.” (PT1, caregiver, 78-year-old female)

Similarly, PT2 explained:

“I get to know some things about dementia, detecting its symptoms, and how to manage and take care of those living with it.” (PT2, 55-year-old female caregiver)

These narratives show that participants did not separate knowledge from action. To “know” dementia was, in their accounts, to become better able to identify it, respond to it, and support someone living with it. Knowledge was therefore framed as deeply practical. It was also social in orientation. PT1's emphasis that such knowledge “can be useful to the community” signals that research participation

was imagined as extending beyond the individual household into a broader collective sphere. The meaning of participation, therefore, was embedded in a wider ethics of communal usefulness.

1B. RESEARCH AS HOPE FOR HEALTH IMPROVEMENT AND RESTORED PERSONHOOD

A second layer of perceived benefit was the expectation that research might lead to improved health outcomes. Participants often spoke about research in aspirational and therapeutic terms, suggesting that it could bring treatment, symptom improvement, or at least some form of recovery. These accounts indicate that the boundaries between research, treatment, and therapeutic intervention appeared blurred in participants' meaning-making.

For instance, PT4, an older adult living with dementia, stated:

“Erm, I think research will be an opportunity to receive treatment for people with dementia. At least, his health should be improving gradually after participating in the research. The overall benefit of doing research is to make that person fit again.” (PT4, 69-year-old male, older adult living with dementia)

Likewise, PT3 remarked:

“Many people living with dementia have died, the research would help improve the memory of those living with dementia in the community.” (PT3, 40-year-old female caregiver)

These statements reveal that research was imbued with hope. The notion of hope reflected a desire for restoration of memory, function, and everyday livability. PT4's phrase, “make that person fit again,” is especially revealing as suggests that dementia may become a threat to personhood, vitality, and social functioning.

This therapeutic framing may also reflect the scarcity of accessible dementia support and treatment within participants' contexts. Where formal services are limited, underdeveloped, or difficult to access, research may come to

symbolize one of the few available spaces where attention, assessment, and potential intervention are offered. Thus, participants' expectations of benefit also point to broader structural absences in care systems. Research is made to carry the weight of unmet clinical and social needs.

1C. STIGMA REDUCTION AND THE RE-SOCIALIZATION OF DEMENTIA

Participants also described research as potentially transformative at the community level, particularly in relation to stigma. Their accounts suggest that dementia is often poorly understood, with symptoms interpreted through moralized or supernatural frameworks. Within this context, research was seen as a vehicle for correcting harmful interpretations and replacing them with more informed and compassionate understandings.

PT2 explained:

"Most people in the community don't know about dementia; the research will help them to detect its symptoms, and seek care instead of stigmatizing and calling anyone exhibiting its symptoms a witch." (PT2, 55-year-old female caregiver)

This account is analytically important because it shows that participants did not see stigma as incidental; they saw it as produced by ignorance, misrecognition, and the absence of accurate knowledge. Dementia symptoms are actively interpreted through cultural lenses that can dehumanize affected persons. The reference to witchcraft is especially telling, as it signals that dementia-related changes may be read not as illness but as deviance or spiritual disturbance.

1D. COMMUNITY ENGAGEMENT AND THE EXTENSION OF RESEARCH INTO EVERYDAY CARE

Participants further valued research when it involved forms of engagement that stretched beyond one-time data extraction. They described the importance of follow-up, community gatherings, and continued interaction, suggesting that research is most meaningful when it remains relational and visible within the community.

PT2 noted:

"Including follow-up visitations, organizing get-togethers to address people living with dementia in the community will encourage them that dementia is not the end of life." (PT2, 55-year-old female caregiver)

This suggests that participants perceived benefit not only in the content of research, but in its mode of presence. Follow-up visits and community gatherings symbolize continuity, concern, and recognition. They communicate that participants' lives matter beyond the moment of interview or assessment. The phrase "dementia is not the end of life" is particularly significant, as it reveals a desire for research to counter not only stigma but social abandonment. Participants wanted research to affirm the ongoing humanity and worth of people living with dementia.

This is further deepened by PT1's account of reusing assessment activities at home:

"I benefited from the aspect where he was asked to draw and write like an arithmetic because it helped him regain his memory, and we apply the same assessment at home before his physiotherapy sessions." (PT1, caregiver, 78-year-old female)

Here, the research process itself became a caregiving resource. The assessment was not experienced solely as a tool for data collection, but as an intervention that could be appropriated into everyday practice. Analytically, this demonstrates how participants actively translated research into care. Rather than remaining passive recipients of study procedures, they reinterpreted and repurposed what they observed. This speaks to participants' agency and to the porous boundary between "research activity" and "care activity" in lived contexts. When research resonates with participants' immediate realities, it can become absorbed into domestic routines as a meaningful form of support.

2. EXPERIENCED BURDENS

Participants identified significant benefits but also reported substantial burdens that complicated their engagement. These burdens were not limited to inconvenience; they often touched on questions of dignity, emotional strain, and the ethics of how research is conducted. Two issues were especially salient: the stress associated with prolonged assessment and the disappointment produced by the absence of feedback after participation.

2A. PROLONGED ASSESSMENT AS STRAIN, FATIGUE, AND ETHICAL DISCOMFORT

Several participants described research participation as physically and emotionally taxing, particularly when assessments were lengthy or repetitive. The problem was not simply that the process took time, but that it demanded sustained concentration from persons already living with cognitive vulnerability, often resulting in exhaustion, irritation, or agitation.

PT1 reflected:

"The assessments took so long that grandpa became tired, agitated, and stressed. I think people with dementia should not be put through such stress." (PT1, caregiver, 78-year-old female)

Similarly, PT5, a participant living with dementia, stated:

"I didn't like the way they were asking me questions at the research. The questions were many and rigorous." (PT5, 63-year-old male, older adult living with dementia)

These accounts reveal that methodological thoroughness may be experienced by participants as interpersonal intensity. What researchers may understand as comprehensive data collection may be felt by participants as pressure, overexposure, or even endurance. This is especially impor-

tant in dementia research, where the capacity to tolerate repeated questioning may be limited and where assessments can inadvertently foreground deficits in ways that are emotionally unsettling.

PT1's comment is especially powerful because it moves from observation to moral judgment: "people with dementia should not be put through such stress." This suggests that the burden of participation was evaluated as ethically questionable. Caregivers, in particular, appeared to assess research procedures through a protective lens, weighing the value of the study against the immediate well-being of their relatives. Participation thus became a site where care ethics and research ethics intersected and sometimes collided.

2B. ABSENCE OF POST-STUDY FEEDBACK AS BROKEN RECIPROCITY

Participants also described the lack of feedback after participation as a significant burden. This was experienced as a breach in the relationship that participation seemed to promise.

PT6 explained:

"I was expecting some information about her health, the feedback of the tests and assessments carried out on her, but to no avail." (PT6, 39-year-old female caregiver)

This statement is analytically rich because it captures the asymmetry participants perceived in the research encounter. They had given time, attention, personal histories, and access to their loved ones' vulnerabilities. In return, they expected at least some form of communicative acknowledgment information about results, clarification about findings, or guidance about what the assessments meant. When none came, participation could feel extractive.

The phrase "but to no avail" carries more than disappointment. It signals futility, suggesting that without feedback, the labor of participation risks losing meaning. This reveals that reciprocity is central to how participants evaluate research. For them, the ethical quality of research is whether the process gives something back in recognizable ways. Feedback, in this context, was a marker of respect, closure, and relational accountability.

3. MOTIVATORS FOR ENGAGEMENT

Participants' willingness to engage in research was shaped not only by altruistic motives or interest in knowledge, but by concrete material realities. Their narratives show that participation decisions were made within the pressures of caregiving, financial strain, and limited access to support. As such, motivators for engagement were closely tied to what research could tangibly offer.

3A. FINANCIAL AND MATERIAL INCENTIVES AS RECOGNITION OF CAREGIVING REALITIES

Participants repeatedly emphasized the heavy financial burden of dementia care and the need for research partici-

pation to acknowledge this reality. Compensation was presented as a fair and necessary recognition of the costs participants already bear.

PT1 stated:

"For me to take part well in research, one is supposed to receive some monetary benefit, because we are spending a lot taking care of grandpa, buying the drugs, diapers, going from one doctor to another." (PT1, caregiver, 78-year-old female)

This quote illustrates that participation is never detached from everyday life. Travel, time, emotional labor, medication costs, and caregiving logistics all shape whether and how people can engage. Monetary support was therefore understood as easing burdens rather than simply incentivizing compliance. It acknowledged that participants were entering research from within ongoing care crises.

Participants also expressed a desire for treatment-related benefits and practical guidance:

"If they promise to give us free treatment, I'll be willing to participate in the research because so many people can't afford it. They should also provide maybe a guide." (PT3, 40-year-old female caregiver)
 "I was expecting that the research will be able to help us with new drugs, what to eat and drink or what not to eat and drink." (PT1, caregiver, 78-year-old female)

These accounts show that participants sought forms of support that were both immediate and usable. Free treatment, dietary guidance, and access to medications represent more than incentives; they are responses to pressing care deficits. Research participation was thus partly motivated by the hope that it might connect families to scarce resources. This again underscores how research becomes entangled with larger failures in health and social support systems.

Even food provision during long sessions was mentioned as meaningful:

"Because they are taking a lot of time while conducting the research, at least they should be providing something the participants would eat." (PT3, 40-year-old female caregiver)

At one level, this is a practical request. At another, it signals the importance of hospitality and care within the research setting itself. Providing food functions symbolically as well as materially: it acknowledges time given, labor expended, and bodily needs.

4. RECOMMENDATIONS FOR PARTICIPATORY PRACTICES

Participants also articulated a clear vision of how dementia research could be conducted more ethically, relationally, and meaningfully. Their recommendations centered on transparency, feedback, preparedness, and stronger relationship-building. Together, these suggestions point toward a participatory model in which research is accountable to those whose lives it enters.

4A. IMPROVED TRANSPARENCY AND MEANINGFUL DISSEMINATION

Participants wanted research findings and care knowledge to be shared more openly and accessibly. They emphasized that results should not remain confined to researchers or institutions but should circulate back into communities in ways that are understandable and useful.

PT1 stated:

“With the use of Television and books, the research results, experiences, care, and other knowledgeable things can be shared, but anonymous to the participants’ identities. All these would at least buffer caregivers’ stress.” (PT1, caregiver, 78-year-old female)

This recommendation reveals that participants valued dissemination not only as information transfer but as emotional and practical support. Sharing results publicly and anonymously was seen as a way to normalize dementia, educate others, and relieve caregivers’ sense of isolation and burden. Importantly, PT1 links dissemination directly to stress reduction, suggesting that knowledge-sharing has psychosocial value. When research findings return to the community, they can validate experience, reduce uncertainty, and equip families with language and strategies for care.

Participants’ concern with anonymity also indicates that they were not indifferent to ethics; rather, they envisioned dissemination that is both protective and inclusive. This suggests a sophisticated understanding of how research can be publicly useful without violating personal dignity.

4B. RECIPROCITY, PRE-ENGAGEMENT, AND RELATIONSHIP BUILDING

Participants also recommended earlier and deeper involvement in the research process. They wanted intending participants to be informed beforehand and oriented to the purpose, procedures, and likely questions of the study.

As PT8 explained:

“Intending participants should be pre-informed and introduced into the research planning so that they won’t be ignorant of some questions during participation.” (PT8, 42-year-old male caregiver)

This account suggests that participation becomes burdensome not only when procedures are long, but when they are unfamiliar, abrupt, or insufficiently explained. Pre-information was valued because it could reduce anxiety, foster preparedness, and create a sense of inclusion. Participants did not want simply to be recruited; they wanted to be brought into the process in a way that recognized their perspective.

This points to participants’ desire for relational legitimacy in research. They wanted to be treated as people whose understanding matters, whose questions are valid, and whose engagement should begin before formal data collection. This recommendation challenges hierarchical research models in which planning happens elsewhere, and participants enter only at the point of extraction. Instead,

it calls for a participatory ethic built on communication, preparation, and mutual regard.

DISCUSSION

This study provides novel insights into how families supporting people living with dementia in Nigeria understood and navigated their participation in dementia research within a context of limited dementia awareness, persistent stigma, and constrained care systems. The findings reveal that research participation by families was interpreted through ongoing engagement within the lens of caregiving realities, social responsibility, hope for health improvement, and access to scarce support. While participants valued research as a source of knowledge, community education, and potential therapeutic benefit, their experiences also exposed structural and relational barriers that sustained complicated engagement, including transportation difficulties, prolonged assessments, inadequate feedback, and concerns around confidentiality and trust.⁷ Our study highlights a critical but often underexplored issue in dementia research which could risk prioritizing recruitment and data extraction without sufficient attention to the ongoing relational, ethical, and communicative processes required to meaningfully engage families over time. Participants’ therapeutic expectations, although reflective of therapeutic misconception appeared to function as both a coping mechanism and a response to broader gaps in dementia care and social support. Our study explains why empirical studies emanating from African countries needs to prioritize participatory and ethically reflexive research approaches that move beyond procedural consent toward sustained transparency, reciprocity, and community partnership. As one of the few studies exploring family experiences of dementia research participation in Sub-Saharan Africa, these findings offer important insights for shaping culturally responsive and trust-centered dementia research practices both within and beyond African contexts.

The findings highlight the broader community-level impact of dementia research participation, extending beyond individual experiences to changes in awareness, attitudes, and engagement. In regions like Nigeria, exposure to dementia-related information is often limited, research participation thus represents a first point of encounter with structured engagement with dementia knowledge. This appears to contribute to the need for dementia literacy, reduced stigma, improved pathways to care, and subsequently improves the quality of life of older adults living with dementia.^{18,19} These findings reinforce the need for intentional, culturally sensitive community engagement strategies in dementia research

This contrasts with reports from global north, where dementia awareness interventions sometimes demonstrate limited community-level impact,^{20,21} likely reflecting differences in baseline knowledge, sociocultural context, and research sufficiency. In settings where dementia discourse is already well established, marginal gains from awareness-focused research may be less visible. Nevertheless, evidence from global north shows that structured engagement can

still foster understanding of dementia, promote dementia-friendly attitudes and social inclusion.²²

Engagement and retention in this study were influenced by a combination of individual, structural and research-related factors. Tangible benefits such as access to health care services, treatment support, free consultations, and financial incentives played an important role in facilitating participation. However, in socioeconomically vulnerable populations, these benefits also raise concern regarding undue inducement, emphasizing the need for strong regulatory oversight and context-sensitive ethical safeguards.^{23–26} This contrasts with findings from high-income settings, where perceived personal benefit appears to play a limited role in decisions to participate in dementia research.²⁷ These differences highlight the importance of tailoring ethical frameworks to local realities rather than applying uniform assumptions across settings.

Participants were recruited from an existing study cohort, which may introduce selection bias, as individuals already engaged in research may differ from those not previously involved in research participation. This may influence the nature of the perspectives captured. However, this prior engagement may also have facilitated richer and more reflective accounts due to familiarity with research processes. While the sample provided rich and in-depth insights, findings should be interpreted within the context of this selected group, limiting transferability to broader populations.

Despite these limitations, the findings are consistent with prior dementia research, participants described intensive or prolonged study procedures as burdensome and, at times, distressing.^{24,28} Nevertheless, the burdens did not negate perceived benefits; rather, both burden and benefit coexisted and jointly shaped willingness to engage. This is demonstrating that research participation decisions often involve negotiated trade-offs rather than simple cost–benefit calculations consistent with evidence from both LMICs and high-income contexts.^{24,29}

The absence of post-study feedback emerged as a notable deterrent to future participation, reinforcing the importance of visibility, reciprocity, and dissemination in sustaining trust and long-term engagement.³⁰ Participants also reflected on the limited involvement of older adults living with dementia and their caregivers in study planning and decision-making across prior dementia research experiences. However, participants viewed such a participatory approach as a means of improving relevance, mutual understanding, collaboration, and community ownership of research outcomes.

LIMITATIONS

A limitation of this study is that data were collected only from participants who consented to participate. Individuals who declined participation may have faced stronger structural, social, or caregiving barriers, and their perspectives may therefore be underrepresented in the study findings. Retrospective accounts of previous research participation may also have been shaped by the passage of time and

subsequent experiences. However, these limitations indicate opportunities for future studies using multi-site studies, longitudinal, and real-time qualitative methods to capture lived experiences more comprehensively and reliably. These participants were drawn from an ongoing World Brain Health Survey, with the eligibility for older adults defined by age (60years or above), clinic attendance, a confirmed diagnosis of dementia, prior exposure to research, and the capacity to provide informed consent or, where necessary, assent supported by their caregiver. All these could have introduced some selection bias because they may be more health and digital literate, than the general population.

CONCLUSION

These findings offer a novel contribution by reframing dementia research participation as a reciprocal, care-enabling process with direct relevance for clinical and social work practice. Rather than treating participants as passive data sources, the study positions engagement as a pathway for trust-building, knowledge exchange, and early support. This study advances an ethically robust, participant-centered model that improves both data quality and therapeutic relationships. In Nigeria's context of a growing dementia burden and absent national strategy, the study reconceptualizes families as co-producers of care and knowledge, with implications for clinical assessment, intervention design, and service delivery. Embedding caregivers, community leaders, and organizations in co-design processes enhances cultural relevance, trust, and uptake of services. The findings underscore caregiver support through education, psychosocial services, and financial assistance as essential to sustainable dementia care, offering a scalable framework for responsive, community-informed practice.

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AUTHOR CONTRIBUTIONS

OE and TF conceived the research, obtained funding, conducted the statistical analysis, and collaborated on writing the manuscript. CO, F.A, and C.E. collaborated on the design of the project and editing the manuscript. O.O collaborated on the conception of the project and writing of the manuscript.

DATA SHARING

Available upon reasonable request, and approval from the ethics committee.

DISCLOSURES

No conflict of interest

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SUPPLEMENTARY MATERIALS

Supplemental Materials

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