



Performing interpretation

An ethnodrama-based method for arts-based dementia research

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Abstract

This study explores how art-based research (ABR) can be used to raise awareness of frontotemporal dementia (FTD) in the United Kingdom. Although drama is often used as a tool for dissemination in health-related research, its potential as a method of interpretation remains underdeveloped. In this study, the art-based method was used to create a narrative, a play called *My Name is Beatrice*, based on autoethnographic conversations and observations and desk-based research. First, the data from observations and conversations, together with findings from desk-based research, were analysed using narrative analysis to develop an understanding of the essential components ethnodrama should encompass. This analysis resulted in the creation of a play. Second, a narrative analysis was conducted, focusing on the structure of the play. This analysis examines the play's construction and

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central findings through key dramatic elements. In this article, ethnodrama is positioned as an analytic tool that highlights cultural silence, stigma, and misdiagnosis while offering new ways of engaging communities and professionals in dialogue about FTD. The intersection of culture, dementia, and the arts highlighted in this study highlights the need for interdisciplinary approaches to dementia research.

Keywords: ethnodrama, narrative inquiry, arts-based research, dementia, diaspora, culture, interpretation

Introduction

Beyond transcription – reimagining interpretation through drama

This article explores ethnodrama as a method for interpreting data in arts-based dementia research. Ethnodrama is a form of creative writing based on diverse research data. It enables the researcher to engage and interpret the research at a personal and emotional level (Saldaña 2005; Sallis 2007). Ethnodrama has been used in diverse contexts including reflective practice, healthcare (Mienczakowski et al., 2002), youth homelessness (Saldaña, 2005), and reproductive health (Ellis & Bochner, 1992).

Ethnodrama remains underutilised within dementia studies, despite its potential to capture and communicate the fragmented, relational, and embodied qualities of dementia narratives. By drawing on narrative inquiry, arts-based research (ABR), and ethnodrama, this study pursues two interrelated aims. First, it seeks to capture the affective and relational dimensions of dementia stories that are often overlooked in conventional qualitative analysis, thereby offering an example of how ethnodrama can be applied in arts-based research. Second, it aims to create culturally relevant artifacts that challenge the silence and stigma surrounding frontotemporal dementia (FTD) in African diaspora communities.

We address these aims by demonstrating how the play, *My Name is Beatrice*, developed through desk research and community observations, can be used to raise awareness of dementia. Through its fictionalised yet culturally grounded narrative, the play illustrates how drama can function simultaneously as research, pedagogy, and intervention, inviting both academic and non-academic audiences into critical dialogue about dementia.

In this article, we present a dramatic script titled *My Name is Beatrice*, which was developed as part of one of the author's doctoral dissertation. The play aimed to

raise awareness and help members of the Nigerian diaspora in the United Kingdom (UK) understand and make sense of frontotemporal dementia (FTD).

Using autoethnography, the researchers critically reflect on storytelling as both a methodological and cultural practice, drawing on insider knowledge to explore ways of raising awareness of FTD within the community. This choice responds to persistent inequalities in dementia care, particularly for underrepresented groups who may struggle to access mainstream services because of cultural, linguistic, or systemic barriers (Sackett et al., 2014; Memon et al., 2016). The first author is a Nigerian Yoruba woman who immigrated to the United Kingdom, making her an insider within this research context. The other authors bring perspectives from their respective cultural and academic backgrounds. The combination of insider and outsider perspectives support both contextual understanding and critical reflection throughout the research process.

Qualitative and narrative research is often conceptualised as a primarily intellectual exercise. Coding and categorisation produce themes, yet such techniques can feel reductive when applied to fragmented, emotionally charged, or culturally complex stories, particularly those of people living with dementia. This study, grounded in autoethnography and arts-based research (ABR), reimagines interpretation through drama, situating the researcher's cultural and narrative expertise as central to methodological innovation. Building on earlier work on ethnodrama in health research (Mieniczakowski, 2001; Saldaña, 2011), this study argues that drama-based interpretation offers a rigorous, culturally sensitive means of exploring dementia experiences in underrepresented communities.

In many underrepresented communities, dementia care is often shaped by traditional health practices and cultural values (Adebisi & Salawu, 2023; Mokwenye, 2025). Families may combine Western medicine with traditional healing methods (Kraut, 1990) or interpret symptoms such as psychosis as signs of spiritual affliction. Such beliefs influence health-seeking behaviours, with families frequently relying on private care or religious interventions instead of formally accessing available services. Recent qualitative research among African populations in London has documented how lay concepts of dementia often interweave biomedical and socio-spiritual frameworks, leading to delayed engagement with the National Health Services (NHS) memory services (Mokwenye, 2024).

A broader scoping review underscores the role of cultural beliefs and stigma in delaying diagnosis and undermining equitable access to dementia care across diverse contexts (Gowda & Gurupasad, 2024). Despite the government and the NHS

initiatives, engagement with community-based dementia programs remains low among the African and African Caribbean populations. These realities underscore the need for sensitive and creative research methods capable of engaging with cultural complexity while generating knowledge that is both academically rigorous and socially impactful. (Carter et al., 2024).

ABR methods extend qualitative inquiry by incorporating multi-sensory, creative, and performative practices, thereby enabling the exploration of marginalised or sensitive issues in culturally responsive ways (Leavy, 2025). Ethnodrama, as one strand of ABR, transforms research findings into dramatic scripts that can be performed for diverse audiences, bridging the gap between research and community engagement (Mienczakowski, 2001). This article positions ethnodrama not merely as a dissemination tool but also as a methodological innovation for interpreting dementia narratives. Therefore, our approach includes the narrative construction of reality and a way of interpreting and becoming aware of the phenomena surrounding us (Bruner, 1991). More specifically, we use the 'narrative inquiry' which signals narrative as a methodological and analytical approach by the researcher (Riessmann, 2008).

Methods

Intertwined research approach

Arts-based research extends qualitative inquiry through the use of artistic forms as both the process and the product of research (Leavy, 2025). ABR methodologies enable researchers to address sensitive or marginalised issues that may be difficult to capture through conventional data collection and analysis. They also allow for the integration of indigenous knowledge systems, oral traditions, and alternative ways of knowing (Tompkins, 1994). A particular strength of ABR is its capacity to move beyond text to engage multiple senses and modes of expression. By enabling multi-perspective and multi-sensory exploration, ABR is well suited to investigating experiences, such as those of people living with dementia, that are relational, embodied, and emotionally complex (Denzin, 2003; Harris et al., 2015).⁵

Within dementia research, ABR has been shown to create inclusive spaces for communication, participation, and the co-production of knowledge (Beard, 2011). Ethnodrama is a form of ABR that involves transforming research data into dramatic scripts, which may then be staged as ethnotheatre or remain as textual artifacts (Mienczakowski, 2001). It integrates the aesthetic assumptions of performance with the theoretical and methodological ambitions of research, offering a means of

⁵ [\(PDF\) 'Critically Evolving: Critical Approaches to Arts Based Research' \(editorial\) UNESCO Observatory Multidisciplinary Journal in the Arts \(open source e-journal\)](#)

presenting findings in ways that are accessible and emotionally resonant to diverse audiences.

For this study, ethnodrama was adopted not only as a dissemination tool but also as an interpretive method that matched the constructivist worldview adopted in this research through narrative inquiry. By creating the play, *My Name is Beatrice*, the purpose was to re-imagine analysis as a performative, embodied, and dialogic process. This article focuses on the development and analysis of the written play as a research-based artistic outcome. This approach recognises that interpretation is not limited to intellectual abstraction but can also take creative forms that evoke empathy, stimulate reflection, and foster dialogue between communities, researchers, and health professionals. According to Novy et al. (2021), there is a methodological gap in dementia research. They suggested that performance-based methods such as narrative inquiry as storytelling could be significant in the field of dementia research in terms of knowledge production.

Autoethnography is an interpretive method that connects personal experiences with wider cultural phenomena, situating the researcher as both participants and analysts. This enables the exploration of hidden, sensitive, or under-researched topics by foregrounding cultural insider perspectives (Jones et al., 2016). Although sometimes critiqued for subjectivity, autoethnography offers strengths for dementia research, particularly where cultural silences and stigma prevent open discussions (Adams et al., 2015).

Scholars argue that knowledge construction is not achieved in a singular manner (Eisner, 2008). Knowledge creation is influenced by a researcher's position, and such positionality is also influenced by some personal characteristics such as age, gender, race, immigration status, beliefs, biases, and emotional responses to participants (Finlay, 2000; Hamzeh & Oliver, 2010; Horsburgh, 2003; Kosygina, 2005; Padgett, 2008). The impact of these characteristics on research cannot be overemphasized. Beyond obvious characteristics such as race or age, "the positionality of the researcher in relation to the data is based on philosophical beliefs and assumptions accumulated throughout a lifetime which inhabit the unknowing mind of the researcher" (Pitard, 2017, pp.1-2).

As a Nigerian immigrant living in the UK, the first author is qualified to create the play from an insider point of view, because she understands the challenges and experiences of the people in her community and can provide culturally appropriate education through the findings.

Some scholars argue that being an outsider might be more advantageous because an outsider can view things overlooked or taken for granted by the insider. However, being an insider or an outsider is seen by some scholars as complex; hence, it is important to see positionality as ever-shifting and permeable (Naples 1996). The playwright's positionality in this research is that of an insider, because of her focus on Nigerian immigrants. Perhaps, if she were to travel to Nigeria to work with people in West Africa, her positionality might be blurred, and she may be an in-between researcher, who is an immigrant living in Western culture and investigating a phenomenon in African culture, in Nigeria.

This blurred positionality would have given her the benefits of being both an insider and an outsider (Ergun & Erdemir, 2010). In the context of this study, autoethnography provided a means of accessing the perspectives of the community. By critically reflecting on cultural knowledge and lived experience, the researchers were able to investigate how dementia is understood and discussed within Nigerian diasporic contexts and how these interpretations influence patterns of health-seeking behaviour, which also represented the narrated reality in this research (Bruner, 1991). The purpose was to build a methodological framework that would be both rigorous and culturally responsive.

This framework enables the exploration of dementia in underrepresented communities by foregrounding insider knowledge, engaging with artistic forms of representation, and producing outputs that are accessible to academic audiences. By situating ethnodrama as an interpretation rather than mere dissemination, this study contributes to expanding the methodological repertoire of dementia research and demonstrates the value of the arts in advancing culturally sensitive inquiry.

Data collection and development of the ethnodrama

The development of the ethnodrama *My Name is Beatrice* followed a cyclical arts-based research process (Jokela & Huhmarniemi, 2018),⁶ moving through phases of informal engagement, desk-based research, and creative transformation. This section outlines the steps taken, highlighting how community conversations and secondary research have informed the construction of the play.

Pre-Data Phase: Informal Conversations and Observations

The research started with the phase of "entering the field," which is often described as a process of familiarization, involving observation, relationship-building, and immersion in the cultural context (Schensl et al., 1999). Prior to creating the play, full

⁶ [Sivut 9-25 Jokela.Timo](#)

cultural immersion was not required as the playwright was already a member of the Nigerian diaspora community. Instead, the pre-data stage focused on informal conversations with friends, acquaintances, church members, and individuals in community clubs, which provided insights into the prevailing beliefs about dementia and healthcare. These were not formal interviews; the questions were informal, such as “do you have any family member with dementia?” or “have you ever heard of Frontotemporal dementia?” or “do you know there are various types of dementia?”

Scholars have argued that informal conversations may constitute the only viable means of generating data in certain contexts (Swain & King, 2022). Moreover, informal and unrecorded interviews are sometimes regarded as the most appropriate approach (Rutakumwa et al. 2020), particularly when addressing highly sensitive subject matter. These conversations revealed that awareness of FTD was almost non-existent within the community. During conversations, some people wanted to know more about the symptoms of FTD. Once symptoms were described, some identified family members or acquaintances who had displayed such ‘behaviours,’ leading them to speculate retrospectively about possible misdiagnosis.

Despite this recognition, there has been limited interest in medical explanations. Symptoms, such as behavioral changes or psychosis, are frequently understood as spiritual attacks or consequences of occult forces, reinforcing reliance on religious or traditional healing. The participants also shared their experiences of caring for relatives with Alzheimer’s disease. In such cases, families tend to rely on private care arrangements rather than community services, such as memory cafés or NHS programs. Many caregivers were professionals in full-time employment who viewed private solutions as sufficient and culturally preferable. These accounts highlight both the silences around dementia and the reluctance to utilize mainstream services, consistent with earlier findings on minority communities’ engagement with dementia care (Memon et al., 2016).

Desk research

To address gaps in community knowledge, the playwright undertook desk research focusing on the epidemiology, symptomatology, and diagnostic challenges of FTD. Literature searches were conducted across major databases and journals, including The Lancet, BMJ, SAGE Journals, and Alzheimer’s Research, UK. This review revealed a notable absence of epidemiological data on FTD in African and African diaspora populations (Alao, 2023).

More recently, Nuytemans et al. (2024) have similarly observed the scarcity of FTD prevalence research in Africa and the Middle East and have called for increased

population-level studies in minority and developing regions. The desk review also highlighted the diagnostic complexity of FTD, which is often misidentified as a psychiatric illness owing to overlapping symptoms with conditions such as schizophrenia, depression, and bipolar disorder (Miller & Llibre, 2019).

Although advances in imaging and molecular characterization have improved diagnostic accuracy (Park & Sun Jun, 2016),⁷ misdiagnosis remains common and has significant implications for families. Additional findings revealed evidence of behavioural symptoms such as hypersexuality, eating disorders, and sleep disruption (McCarter et al., 2016; Burrell & Hodges, 2018; Aiello et al., 2016).

The literature further underscores the role of genetic predisposition, with estimates suggesting that approximately 40% of FTD cases have a familial component (Khan & De Jesus, 2021).⁸ However, genetic research remains limited to African populations, with less than 2% of genome-wide association studies including African data (Akinyemi et al., 2022). This absence not only restricts the global understanding of FTD but also contributes to structural inequalities in diagnosis and treatment.

The play

The ethnodrama *My Name is Beatrice* explores frontotemporal dementia (FTD) through the story of Beatrice, a 43-year-old Nigerian immigrant nurse in the UK, and her teenage daughter, Ireti. The play captures the emotional and cultural complexities of dementia by combining clinical knowledge, community observations, and dramatic structure. At the start of the play, we get to know the two main characters, Bee and Ireti, as they bond. We are also introduced to Eileen, Bee's friend. As Bee's condition degenerates, her daughter, Ireti, is plunged into a hellish abyss, especially as her aunty, the only extended family she has, thinks her mother is demonically oppressed and is doing everything to exorcise the demons. Bee is misdiagnosed, and we see the horror of FTD as her personality changes. Ireti does not give up but forges on in her quest to help her mother until Professor Omole comes on the scene. She is like a lifesaver for the family. Later in the play, Bee is diagnosed with FTD after an initial misdiagnosis. She is placed on some medication, though there is no cure for her FTD.⁹

⁷ [\(PDF\) Frontotemporal Dementia](#)

⁸ [Frontotemporal Lobe Dementia - StatPearls - NCBI Bookshelf](#)

⁹ The play is published and available in the Lauda database of the University of Lapland (Alao, 2023). [Raising Awareness of Frontotemporal Dementia among Nigerian Immigrant Communities, in the UK, through Storytelling](#)

Analyses

First, the data from observations and conversations, together with findings from desk-based research, were explored to develop an understanding of the essential components that ethnodrama should encompass. These included the chosen dramatic form, in this case, a play, and the elements to be incorporated. This stage represents a form of narrative analysis (Polkinghorne, 1995), aiming to construct a meta-narrative from the data and thereby address the first aim of this article.

To achieve the second aim, an analysis of the narrative (Polkinghorne, 1995) was conducted, focusing on the structure of the play. This examined the play's construction and central findings through key dramatic elements: characterization, dialogue, plot, intertextuality, setting, spectacle, and theme (Smiley, 2005).

Ethics

This study reflects on creative methods in art-based dementia research. The methods here are intertwined and constantly discussed within the research process. The selection and development of the methodology were based on the first author's subjective life experiences concerning dementia within different contexts over a long period of time. It has been suggested (Edwards 2021) that autoethnographic methods require multidimensional ethical reflection and strong integrity because of their nature in the knowledge production process. The first author's background as an African Yoruba woman can be situated within indigenous contexts due to notable similarities. Here an Indigenous scholar expresses her ethics in knowledge production in the following way:

My knowledge is not just coming from me, or from books and articles accessed because of my exclusive university library membership. My knowledge primarily comes from my family, my communities, my connections. My "self" belongs to them. Therefore, I must constantly be reflecting on "Who do I speak for?" "Whose stories and knowledges am I able to share?" alongside, "What am I speaking for?" and "Who am I speaking to?" (Bishop 2020, p. 6).

We are aware of ethical considerations during the research process, especially ethical issues surrounding the use of informal chats or interviews as data. Some scholars argue that such chats should be categorized as interviews, even if they are informal, while others describe the researcher or interviewer who is prodding or asking questions as someone with the agenda of data collection; hence, they are deceptive because the interviewee divulges information, thinking they are just having an informal chat (Hammersley & Atkinson, 2007). To mitigate potential ethical

concerns, during informal conversations with community members, the first author explained her research interests and described her ongoing efforts to promote awareness of FTD within the community.

Findings

A central finding of the study is the cultural silence surrounding dementia in Nigerian diaspora communities. Conversations revealed limited recognition of FTD, with symptoms frequently attributed to spiritual or supernatural causes. This aligns with earlier research showing that underrepresented groups often interpret psychiatric or neurodegenerative symptoms through cultural or religious frameworks (Memon et al., 2016). Such interpretations can delay medical consultation, contributing to misdiagnosis or late diagnosis (Onyike & Diehl-Schmid, 2013).

Creation of the ethnodrama My name is Beatrice

The ethnodrama was written through an iterative creative process, drawing on the cultural insights gained from community conversations and the scientific knowledge synthesised through desk research. Characters were designed to reflect believable Nigerian names, values, and experiences, while dramatic elements captured both the medical realities of FTD and the cultural interpretations that shape community responses.

The first draft of the play was shared with colleagues who are playwrights and stage directors for feedback. Initial critiques emphasised the need for greater exploration of the mother–daughter relationship between the main characters, Beatrice and Ireti. In response, an additional opening scene was created, portraying hair-braiding and storytelling to foreground familial intimacy before the onset of illness. This adjustment balanced the narrative hook of beginning in medias res with the need for audience connection to the characters.

Throughout the writing process, ethical considerations were addressed by ensuring transparency in the transformation of research material into fictional form (Candy & Edmonds, 2018). While the play drew on published sources and cultural observation, no direct human participants were involved, eliminating the requirement for formal ethical review. Nevertheless, care was taken to represent dementia sensitively and to provide cultural and contextual framing to avoid misinterpretation.

The elements of drama and how they help raise awareness of FTD

Characterisation

Characters are central to drama; they function as embodiments of human struggle and cultural meaning (Wood, 2011). In *My Name is Beatrice*, Ireti emerges as the

protagonist whose journey to secure a diagnosis for her mother reflects the burden carried by young carers (Allen et al., 2009). Her decisive and resilient traits enable her to confront both medical authority and cultural pressures. For instance, Ireti stands up to her aunt, Ladun, and a group of “prayer warriors” attempting to “exorcise” Beatrice, symbolising the clash between biomedical explanations and spiritual interpretations of illness.

Ireti: /She hasn't got an evil spirit! What she needs is a doctor, not a freaking Wolii and some smelly water...

Ladun: (Arms akimbo) When? From your mouth, Ireti? 'Freaking Wolii'?

Ireti: I'm not going to sit here with you while that weirdo hurts Maami! She's ill, and you're freaking her out.

Ladun: (Stands in front of her) Where do you think you're going?

Ireti: To save my mother from you horrible lot!

Beatrice (Bee), in contrast, is portrayed with both tenderness and decline. Initially presented as a nurturing mother engaged in hair-braiding and storytelling, her progression into aggression, aphasia, and inappropriate behaviour highlights the disintegration of her social identity, a common feature of FTD (Burrell & Hodges, 2018). This character explicitly reveals the burden of FTD to the audience.

Ireti: Maami, it's getting a little embarrassing now, you singing that song to me every time you make my hair. I'm going to be 16 soon.

Bee: My darling, a child is never too old to be pampered by her mother...

(Bee continues singing and swaying.)

By juxtaposing Beatrice's pre-illness character with her symptomatic changes, the play illustrates the disruptive impact of dementia on selfhood and family bonds.

Eileen: Sorry to barge in on you. If it's not a good time, I'll/

Bee: /You're right, not a good thai...time.

(Eileen makes to leave.)

Ireti: Why are you leaving? Are you afraid she'll bite you?

Eileen: What's come over you, Ireti?

Ireti: (Dramatically) What's come over you, Ireti? Ha ha ha. I've been drinking holy water and...

(Bee draws close to her and slaps her.)

Bee: Get out! Bastard!

Eileen (Drops her bag) Bee!

(Ireti exits stage, crying.)

Supporting characters such as Eileen, a family friend, and Professor Omole, a clinician, provide alternative perspectives that balance despair with resilience. Collectively, these characterisations illuminate the cultural silences, relational conflicts, and coping strategies that shape Nigerian diaspora experiences of dementia.

Dialogue

Dialogue in ethnodrama functions as both narrative device and cultural representation. It reveals character traits, advances the plot, and situates the story within a specific cultural milieu (Saldaña, 2011). In *My Name is Beatrice*, dialogues range from affectionate banter between mother and daughter to confrontational exchanges reflecting the strain of caregiving.

For example, the opening scene's seemingly mundane conversation between Beatrice and Ireti about hair-braiding demonstrates intimacy, humour, and cultural continuity:

Bee: There you go, my princess. You look smashing!

Ireti: (Hugs Bee) Aww, thanks. Love you.

Bee: I love you too, my darling. Very much.

Ireti: (Looks at her hair in the mirror above the fireplace) That'll last for another month.

Bee: A month? I'm redoing that hair in two weeks, just before you go to Bath.

Ireti: Mum, I'll show my gratitude by cooking dinner tomorrow.

Bee: Nope! I'll cook, and you'll help.

Later, dialogue conveys the breakdown of communication as Beatrice's illness advances. She interrupts conversations with profanity, shocking her daughter and friends. Such moments highlight the alienation families experience when familiar relational patterns collapse due to neurodegeneration (Aza et al. 2022).¹⁰

Ireti: My friend is coming today.

Bee: What friend?

Ireti: Anna from school. We're just gonna hang out.

Bee: NO ONE is come...coming into this house. Understand?

Ireti: But you like Anna. You braided her hair once, remember?
Anyway, she's already on her way.

Bee: Your mobile phone still working then?

Ireti: Yeah, why?

Bee: Then phone her, DUMB ASS! Tell her your mother said NO VISITORS!

Ireti: No! I won't call her. YOU will have to explain why YOU don't want her here!

Bee: You bet I will.

The play also employs overlapping speech, represented with forward slashes, to simulate naturalistic interruption and conflict. This device captures heightened emotion and mirrors the messiness of real-life conversations (Ivanchenko, 2007).

Plot

The play follows a classic three-act structure (Field, 2005), progressing through setup, confrontation, and resolution.

¹⁰ <https://pmc.ncbi.nlm.nih.gov/articles/PMC9077340/>

Act I introduces Beatrice, Ireti, and Eileen, establishing familial warmth before FTD symptoms emerge.

Act II presents the rising action, with misdiagnoses, family conflict, and Ireti's growing desperation.

Act III delivers the climax and resolution, as Professor Omole correctly diagnoses FTD and introduces creative arts as a therapeutic pathway.

This structure mirrors the trajectory of illness narratives, from initial signs and misinterpretation to eventual recognition and adaptation. It also underscores the tension between uncertainty and clarity in dementia diagnosis (Miller & Llibre, 2019). One of the burdens of FTD is the threat of an impediment to normal development in children and young people who care for their parents. This usually happens when a young person responds to the perceived threat of the loss of a vulnerable parent by trying to take responsibility for that parent's physical care and emotional well-being (Allen et al., 2009).

We see Ireti's development as she decides to research her mother's condition. A fundamental point in character development is that they learn new skills and become aware of who they are and their capability to deal with their problems.

Professor Omole: Talk to me, Ireti. How do you know that your mother doesn't have depression?

Ireti: From online.

Professor Omole: Online?

Ireti: I've been looking up her symptoms.

(Professor Omole Nods.)

Intertextuality

Intertextuality enriches the play by layering meaning through the integration of familiar cultural forms. In its simplest meaning, this device is the concept of texts borrowing words and concepts from each other. Intertextuality is attributed to Julia Kristeva, who coined the usage in the 1960s (Martin, 2011). James Joyce's *Ulysses* said to be a retelling of *The Odyssey*, is an example of intertextuality in literature.

Two devices are central in the use of intertextuality in *My Name is Beatrice*:

Fable: The Yoruba story of the tortoise and the one-eyed lion is introduced in the opening scene but left unfinished until the play's conclusion, symbolising disruption and resolution. The fable provides a metaphor for confronting "bullies," with FTD positioned as the ultimate adversary.

Haiku poetry: Beatrice, despite experiencing aphasia, discovers a new passion for writing Haiku poems. This reflects evidence of paradoxical functional facilitation in FTD, where artistic creativity may emerge despite neurological decline (Kapur, 1996; Erkkinen et al., 2018). The Haiku serves as poetic snapshots of Beatrice's inner world, offering audiences insight into her shifting consciousness.

Setting

Settings such as the family home, church gatherings, and hospital consultations anchor the narrative in everyday spaces while highlighting cultural tensions. The home is depicted as both a place of intimacy and a site of distress, cluttered with signs of Beatrice's illness. The hospital, meanwhile, represents both failure (misdiagnosis) and eventual hope (accurate recognition by Professor Omole). By carefully situating scenes, the play contextualises the challenges of navigating healthcare systems while grappling with cultural interpretations of illness.

Spectacle

Spectacle refers to the visual and performative elements that evoke strong audience reactions (Aristotle, 1977). In *My Name is Beatrice*, spectacle is most evident in the exorcism scene, where "prayer warriors" attempt to cast out "demons." Costumes, chanting, and ritual create dramatic intensity while critiquing exploitative practices within some religious communities. The scene functions not only as theatrical climax but also as social commentary on the risks of spiritualising dementia symptoms.

Theme

The central theme of the play is the tension between biomedical and cultural interpretations of dementia. Sub-themes include caregiving burdens, misdiagnosis, and the role of narrative medicine in fostering empathy (Charon, 2006). By contrasting the dismissive approach of Dr Baines with the attentive listening of Professor Omole, the play highlights the importance of narrative competence in clinical practice.

Thematically, *My Name is Beatrice* also critiques stigma and silence in diaspora communities, demonstrating how storytelling can invite dialogue and challenge cultural taboos (Lewis, 2011; Green & Brock, 2000).

Discussion

The ethnodrama *My Name is Beatrice* demonstrates how drama can serve as both interpretation and intervention in dementia research. By embedding lived experience, cultural knowledge, and clinical insight into a dramatic narrative, the play illuminates the social and emotional complexities of frontotemporal dementia (FTD) in Nigerian diaspora communities. This discussion situates the findings within wider debates about dementia awareness, narrative medicine, and the role of arts-based research (ABR). The findings from *My Name is Beatrice* highlight three overarching insights. These three core findings are further discussed next.

Dementia awareness and cultural interpretations: Dementia narratives in Nigerian diaspora communities are shaped by silence, stigma, and alternative health beliefs. A key insight emerging from this study is the pervasive silence surrounding dementia within Nigerian diaspora communities. Many conversations indicated that frontotemporal dementia (FTD) is rarely recognised, with its symptoms often explained through spiritual or supernatural interpretations. This observation echoes previous findings that highlight how marginalised groups may understand psychiatric or neurodegenerative conditions within religious or cultural belief systems (Memon et al., 2016). Such culturally rooted interpretations can hinder timely medical engagement, leading to delayed or inaccurate diagnoses (Onyike & Diehl-Schmid, 2013).

The play also highlighted reliance on private care and informal networks rather than mainstream dementia services. These findings echo broader evidence that African and African-Caribbean families in the UK are less likely to access memory clinics or participate in community-based interventions (Healthcare for London, 2009).¹¹ The reasons include mistrust of health institutions, lack of culturally tailored resources, and the persistence of stigma (Mukadam et al., 2011). These barriers underscore the importance of developing culturally responsive strategies that acknowledge and respect community beliefs while promoting accurate understanding of dementia.

Young carers and intergenerational strain: Young carers shoulder significant emotional and practical burdens, often navigating healthcare systems with limited support.

The portrayal of Ireti in *My Name is Beatrice* illustrates the heavy burden borne by young carers. As a teenager, she assumes responsibility for navigating healthcare systems, resisting cultural pressures, and managing her mother's behavioural

¹¹ <http://www.londonhp.nhs.uk/wp-content/uploads/2011/03/09-Dementia-EqlA.pdf>

symptoms. Research indicates that young carers in minority communities often experience compounded stress due to intergenerational expectations and limited institutional support (Allen et al., 2009; Joseph et al., 2019).

The play's narrative of a young carer advocating for recognition of her mother's illness highlights the urgent need for health services to provide not only clinical support but also psychosocial resources for carers. This aligns with calls for a family-centred approach in dementia care that integrates medical, cultural, and relational perspectives (Beard, 2011).

Arts-Based Research and Ethnodrama as Method: Ethnodrama offers a powerful means of interpreting and communicating these experiences, enabling both academic and community audiences to engage with the cultural and emotional dimensions of dementia.

This study also advances the methodological contribution of ethnodrama. While ABR has been increasingly applied in health research (Leavy, 2025), ethnodrama remains relatively underutilised in dementia studies. The findings suggest that ethnodrama provides a powerful means of interpretation by:

Capturing emotional and relational dimensions of illness that elude thematic coding.

Bridging academic and community audiences, by making research accessible and impactful.

Challenging cultural taboos by dramatising sensitive issues in ways that stimulate dialogue.

Importantly, the play demonstrates that ethnodrama can serve not only as dissemination but as an analytic process (Saldaña, 2011). By transforming narrative data into performance, the method allows for the exploration of silences, conflicts, and contradictions that are often flattened in conventional analysis.

The narrative analyses can be reviewed through criteria such as reflexivity, historical continuity, dialectics, evocativeness, and workability (Heikkinen et al., 2012).

Reflexivity in this research referred to the understanding of ontological assumptions about reality: the idea that narratives are socially negotiated and constructed was the foundation throughout this research process. Alongside pursuing transparency in creating the play and analysing its contents, we aimed to create historical continuity to the meta-narrative that the research constructs (Salmela & Uusiautti, 2017).

The principle of dialectics was specifically present in the pre-data phase and when doing the narrative analyses. It will occur again through sharing the play with the audience. The social construction appears also through evocativeness that this research and the metanarrative, the play itself, may present. The purpose in narrative is not to reach the truth itself but to express rhetoric strength and have resonance with the audience's experiences. Workability refers to the pragmatic nature of research, which in this case becomes materialized as the implications and uses of the play among the target audience.

Conclusion: Towards culturally responsive art-based dementia research

The intersection of culture, dementia, and the arts highlighted in this study points towards the need for interdisciplinary approaches to dementia research. Traditional epidemiological and clinical methods, while vital, cannot fully capture the lived complexities of underrepresented groups. Integrating arts-based interpretation can broaden the scope of inquiry, contribute to culturally sensitive awareness campaigns, and foster empathy across cultural divides.

Furthermore, the representation of Beatrice's paradoxical creativity through Haiku poetry highlights the potential of ABR to uncover new dimensions of resilience and expression in dementia. Recent evidence further strengthens this claim: for example, Zhuo et al. (2025) demonstrated that a structured expressive arts intervention improved communication and reduced behavioural symptoms in people with dementia, while Petrovsky et al. (2025) showed that musical arts participation correlated with slower cognitive decline. These studies affirm and extend earlier work (Erkkinen et al., 2018; Zeilig et al., 2019).

This study demonstrates the value of ethnodrama as an innovative interpretive method for examining dementia narratives in underrepresented communities. By transforming research findings into a dramatic script, *My Name is Beatrice* makes visible the cultural silences, misdiagnoses, and caregiving burdens that often remain hidden in conventional academic texts. By drawing on narrative inquiry, arts-based research, and ethnodrama, article seeks to go beyond transcription and coding to capture the embodied, emotional, and relational dimensions of dementia experience (Lewis, 2024; Capstick, 2023). It also aims to view storytelling and performance not merely as dissemination tools but as inquiry in their own right (Brand et al., 2024). In this way, ethnodrama functions simultaneously as research, pedagogy, and intervention.

The play highlights both the structural barriers to early diagnosis, such as stigma, misrecognition of symptoms, and cultural mistrust of biomedical care, and the possibilities of arts-based research for challenging these barriers. Importantly, the fictionalised but culturally grounded narrative of Beatrice and Ireti illuminates how FTD intersects with diasporic identities, faith practices, and intergenerational care. Such an approach broadens dementia scholarship by attending to voices and perspectives often marginalised in mainstream epidemiological and clinical studies (Ochieng, 2011; Akinyemi et al., 2022). The play thus contributes not only to awareness-raising but also to the development of culturally responsive frameworks for dementia care.

Future work should expand the reach of research-informed theatre by staging ethnodrama in diverse community and clinical contexts, followed by facilitated discussions with audiences. This aligns with calls for participatory, socially engaged research methods that bridge gaps between medical science, lived experience, and cultural practice (Gray & Malins, 1993;¹² Julia et al., 2015). Moreover, by situating dementia within broader narrative and performative traditions, including those of African diasporic and Indigenous communities, the method affirms storytelling as a vital epistemology in health research.

In conclusion, *My Name is Beatrice* demonstrates that drama-based interpretation is not only a rigorous methodological innovation but also an ethical and culturally sensitive way of engaging with dementia. It underscores the urgent need for interdisciplinary approaches that harness the arts to foster empathy, challenge stigma, and support earlier recognition of dementia across diverse populations.

Author contributions

The first author, Dr. Abimbola Alao conceived and led the study, developed the play that formed the basis of the research, conducted the original fieldwork, and led the manuscript writing. Alao also contributed important insider perspectives to the study design, interpretation, and cultural contextualization.

The second author Associate professor Erika Katjaana Sarivaara brought her expertise on studying minorities and using autoethnography as a method. Sarivaara contributed on writing, methodological considerations, data interpretation and critical revision of the article.

Professor Satu Uusiautti served as the responsible supervisor of the original study implemented by Dr. Alao at the University of Lapland, Finland. Her expertise in

¹² <http://carolegray.net/Papers%20PDFs/epgad.pdf>

educational psychology and qualitative research methods contributed to the design and implementation of research. She also participated in drafting the research article.

Associate professor Syed Javaid role in the study was as a later-life academic psychiatrist with a specialist interest in dementia prevention, diagnosis, and management. He contributed to the ethical discussions and critical review of the original paper, ensuring that the manuscript remained sensitive to both diagnostic complexity and the lived impact of dementia. As an external contributor, he also brought a degree of analytical distance, allowing him to question assumptions, and support ethical discussion around cultural interpretation, community portrayal, and dementia-related vulnerability.

All authors contributed to the analysis, writing, review, and editing of the manuscript and approved the final version for publication.

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