

Ways to Collaborate Patient Partners with Dementia from Racialized Communities to Create Culturally Safe Dementia Care Practices

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Background



Underrepresentation in Dementia Research

Dementia in racialized communities and their experience of navigating healthcare is often underrepresented in research and healthcare practices (1)



Structural and Systematic Barriers

Structural and systemic barriers associated with culture, language, and identity contribute to inequitable access to healthcare resources negatively affect the dementia experiences of racialized communities (2)



Power of Patient Partners

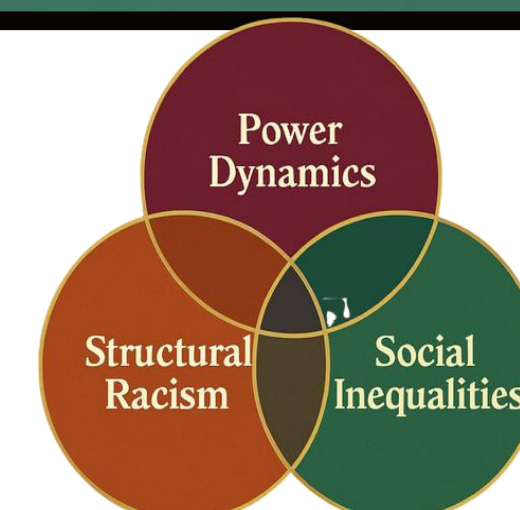
Engaging older adults living with dementia and their caregivers as patient partners can amplify the voices of those often overlooked at the system and practice levels and address the need for culturally safe dementia care in healthcare settings (2)

Objective

The aim of this study is to explore ways to support and encourage the involvement of racialized older adults living with dementia and their caregivers as patient partners in dementia research. This paper is a sub-study of the doctoral project.

Methodology and Framework

In this interpretive descriptive qualitative study, we are using intersectionality theory and a patient-oriented research framework to examine how power dynamics, structural racism, social inequities, and discrimination shape experiences of dementia diagnosis and access to healthcare resources in racialized communities



Results: Ways for Meaningful Engagement

Relational & Cultural Foundations

Prioritize Long-Term Rapport

Allow sufficient time to build genuine relationships through consistent and respectful engagement.

Implement Culturally Safe Approaches

Use trauma-informed practices and ensure active participation of people living with dementia.

Respect Perspectives and Identity

Demonstrate respect for cultural identity through both verbal and non-verbal communication.

Team Composition & Community Integration

Diversify the Research Team

Include bicultural and bilingual researchers to strengthen communication and cultural understanding.

Practice Researcher Reflexivity

Stay self-aware of personal biases and practice appropriate self-disclosure to build authenticity.

Build Active Community Partnerships

Partner with religious organizations and participate in local volunteer activities to strengthen presence.

Tips For Novice Researchers

Self-Care and Emotional Awareness

Reflexivity and Frequent Debriefing

Navigating Lived Experience as Researcher, Caregiver and Healthcare Provider

Maintain Professional Boundaries and Time Management

Outcome

Culturally safe dementia care cannot be achieved without the meaningful involvement of racialized communities living with dementia to decrease the risk of excluding their voice in redesigning healthcare practice in dementia care



References:

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