POS17-11 “We’ll keep chipping away”: a joint learning journey for a Caribbean co-researcher and a university researcher to raise dementia awareness amongst Caribbean communities

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Background

- Dementia diagnosis rate amongst African and Caribbean people significantly lower than the white UK population
- There are long-standing cultural, societal and service provision reasons that make many black people reluctant to seek mainstream dementia support
- Researchers often struggle to recruit African and Caribbean public members as co-researchers, or as study participants

Our approach

- Secured funding to employ BW as a long-term (2yrs+) co-researcher through OM’s fellowship funding
- BW introduced OM to local Caribbean “Elders’ Clubs” at various locations
- Repeat visits to local Elders Clubs to provide informal, interactive ‘dementia talks’ co-facilitated by OM and BW
- Develop culture-specific dementia information leaflets & Caribbean resources for Cognitive Stimulation Therapy sessions
- Providing training opportunities for two Caribbean co-researchers
- Trying to engage religious leaders to ‘normalise’ talking about dementia amongst Caribbean communities

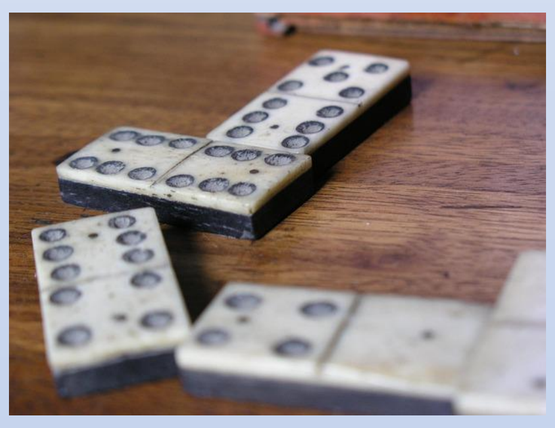
Initial Community Response

What’s in it for us?

“We are fed up with University Researchers They take information away, and they don’t feedback to us”

What we really need is a culturally appropriate, local day service with transport for Caribbean elders – not RESEARCH

We don’t talk our private business in public



Many older male members preferred to continue with the game of dominoes rather than joining in our dementia talk

“We’ll keep chipping away” -what we’ve slowly achieved

After your talk, xx went to see their doctor

I am willing to talk about my family’s dementia journey, if you can provide a private space (within a community hall)

A joint learning journey

Asking what the community’s priority is, to develop a research question, may be a good principle of co-production. However, what the community really want/ need (e.g., “we want doctors who can spend more time explaining things (symptoms) to us”, “we want a free transport to help Caribbean older adults to get to a day centre”) is often beyond the capacity of a research group.

It was important that the co-researcher, a trusted community member, often stepped in to clarify what a researcher can do/ cannot do, emphasising the length of time it often requires to conduct a research project. Co-presenting dementia talks helped to reduce some of ‘research scepticism’ in the community.

The ‘cultural norm’ of our local Caribbean communities is still that dementia is not discussed openly. Changing long-standing ‘norm’ requires continuous efforts from both researchers and community members to build trust and collaborative relationships.

We still need to keep *‘chipping away’*, as aptly summarised by the co-researcher.

‘Skilling-up’ co-researchers and other community members – whether sharing dementia knowledge and signposting services or supporting them to attend relevant training courses and conferences – is essential to ensure that knowledge is passed onto our community beyond the project duration.

Recommendations

- Before your work starts, clarify what researchers need from communities, and have a clear agreement on a shared goal. Be explicit about the funding/ timelines, if projects are time-limited
- Frequent, ‘bite-size’ feedback to communities is essential to keep communities engaged and to build trusting working relationships

Conclusion

Long-term involvement of co-researchers throughout a research project is essential particularly when working with diverse communities. However, this requires researchers to secure sufficient funding in advance and have a system in place to allow longer-term employment of community researchers.

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