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Tackling stigma and increasing understanding of dementia in Kenya: The ENGAGE research project

Community members developing dementia awareness-raising messages in Meru Kenya



Dementia impacts almost every one of us in one way or another; The person living with dementia, the carer(s), the family, and the community in which the person with dementia resides. One of the greatest challenges of having dementia or a family member with dementia is the stigma attached to it, which perpetuates social exclusion. This is common even in contexts where attempts have been made to raise public awareness and create dementia inclusive and friendly communities in higher income countries.

Stigma can make the person with dementia withdraw from friends, social and community events. Those who support the person with dementia may feel shame and equally withdraw from their social and community networks. The community may also play a big role in perpetuating the isolation of those affected by dementia, particularly if they lack the understanding about the condition.

In sub-Saharan Africa (SSA), particularly eastern SSA, the number of people living with dementia will increase significantly in the coming years (from approximately 600,000 in 2019, to 3 million in 2050) [1]. Kenya is one of the countries in the region expected to register a sharp increase in the number of people with dementia (from approximately 87,000 in 2019 to 360 000 in 2050) [1]. Despite this projected increase, there is lack of diagnosis, limited knowledge, and awareness of dementia; most often it is believed to be a normal part of aging, with most believing that as we age, we are likely to develop signs and symptoms associated with dementia. The lack of knowledge in this context is pervasive; the public and most health care practitioners [2] do not understand dementia, and may attribute it to witchcraft or other supernatural causes. What this means is that people with dementia and those caring for them remain unsupported. The lack of national dementia policies and strategies in Kenya and indeed most SSA countries [3] that could help the development and implementation of health and social care services for people with dementia and those who provide care, further delays the ability to promote their health and well-being.

Recognising these challenges, we are conducting a research project -ENGAGE- that examines how people living with dementia in rural Kenya can be better supported by their neighbours and other community members to stay connected and actively engaged. Countries like the UK have demonstrated that supportive neighbourhoods can promote the health and well-being of people with dementia and their carers [4]. Our project aims to raise dementia awareness while highlighting the unmet social and healthcare needs of people with dementia and those who support them in rural Kenya.

We are doing this by using participatory qualitative research approaches, that include creative approaches, such as designing awareness-raising messages, developing role-

plays, theatre productions and short documentaries. The learning, experiences and outcomes from this process will inform the development, refinement and implementation of a ‘neighbourhood’ or community-based model of support and understanding in the context of dementia in rural Kenya. To fulfil the aim of the ENGAGE project, we had to think carefully about how to research dementia in a country where diagnosis is rare, stigma is high, and where dementia and often a taboo topic. At the planning stage of the project, we set up a Community Advisory Team to ensure that the project can build on local knowledge, contextual and socio-cultural factors.

The Community Advisory Team supporting ENGAGE in Kenya



The team comprises 10 community members (of diverse ages and genders) in Meru County. Meru county is one of the 47 counties in Kenya located in the east of Mount Kenya. The team includes individuals from local organisations supporting older adults, those working or volunteering with health and local agencies, and also community members with no role in any of these formal organisations. This group brings diverse

skills and experiences to the project and serves as a vital link between the research team (researchers from Kenya, UK, and Ireland) and the local community in Meru, providing expert knowledge, lived experiences and logistical support in relation to the project. Given the limited knowledge about dementia in Kenya, we asked the team to identify their training needs at the planning stage of this project. The identified needs informed the development of a training on ‘Understanding Dementia’ which was delivered by Purity (the project lead) who is familiar with the local context.

This work also entails collaborating with Dementia Associates (people with a lived experience of dementia) based at the Salford Institute for Dementia in the UK. With support from the research team, the Community Advisory Team developed logos and messages that can be printed on t-shirts and other promotional materials such as banners.

T-Shirt prototypes developed by the Community Advisory Team



Dementia Associates in the UK offered their comments and suggestions on the work of the Community Advisory Team. Dementia Associates are passionate and thrive in an environment where they can share their lived experience of dementia to dispel myths, educate and advocate for a more inclusive society. According to Maraki Pocsai, the Community Engagement Officer at the Salford Institute for Dementia, who has been facilitating these cross-cultural engagements; *“Two groups in two different continents working together to impart change; that experience is described by a Dementia Associate as ‘worth getting up and being a part of. It makes you feel good’”*



We contend that the development of a model, approach or a strategy that aims to tackle stigma, promote social inclusion and acceptance for people with dementia, ought to employ innovative approaches, ensuring that potential beneficiaries are meaningfully involved in a culturally acceptable and ethically appropriate manner. Involving people with dementia to be a part of this has been crucial, not only to help break down some of the taboos around dementia in Kenya, but it has equally provided Dementia Associates with an opportunity for their experience and knowledge to be used to support others. We believe this to be one- if not the first project- that has involved people living with dementia in a Western context to support the development of awareness-strategies in an African country and, if successful, might be an approach that others adopt.

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You can find out more about the ENGAGE project [here](#)

References

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