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INTEGRATION AND EVALUATION OF A COMMUNITY-LEVEL DEMENTIA SCREENING
PROGRAMME IN KENYA (DEM-SKY): A PROTOCOL

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RUNNING TITLE: DEM-SKY PROTOCOL

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ABSTRACT

Background: In Kenya, many people are currently living with dementia without a formal diagnosis or support; often attributing symptoms to normal ageing or as a consequence of past behaviours. Dementia screening is not commonplace within Kenya. Improving the supply (or *opportunity*) of dementia screening within the region may promote uptake, thus leading to more people to seek a formal diagnosis and subsequently receive support within the Kenyan healthcare system. Community Healthcare Workers (CHWs) have successfully demonstrated their value in delivering health interventions within Kenya and have strong links within local communities.

Objective: To integrate and evaluate a community-level dementia screening programme among older adults in rural Kenya.

Methods: Through leveraging this resource, we will deliver dementia screening to older adults (≥ 60 years) within Makueni County, Kenya over a 6-month period. Here, we present a protocol for the process evaluation of a dementia screening in Kenya (DEM-SKY) programme. The process evaluation seeks to understand the adoption, implementation, continuation and implementation determinants, using quantitative and qualitative measures.

Results: Findings for this programme will be published in 2023.

Conclusions: Gaining perspectives of different participants involved in the programme (i.e., older adults, CHWs, hospital staff and trainers), will ensure that we understand the reason for successful (or unsuccessful) delivery of DEM-SKY.

Key words: diagnosis, middle-income, evaluation, Africa, implementation

INTRODUCTION

Within Low and Middle Income Countries (LMICs), Sub-Saharan African countries have the fastest growing rates of older people [1]. In Kenya, the population aged 60 years and older was 4.3% in 2017 and is expected to reach 10.6% in 2050 [2]. Modelling suggests that there are over 86,000 people currently living with dementia [3]. However, primary data on dementia prevalence within Kenya is sparse, with no national or centralised healthcare database, and best quality data is derived from non-representative cross-sectional estimates (19.7% of probable dementia) [4]. Kenya has limited long-term care services for older adults, including dementia care with unknown dementia prevalence [5]. The little we know about dementia in Kenya is derived from studies involving the few individuals who receive a diagnosis, but typically in the more advanced stages of the condition when carers have reached a crisis point. Screening may be one solution to promote pathways to diagnosis, treatment and support [6], though at present dementia screening is not routine practice within Kenya. This paper describes the Integration and Evaluation of a Community-Level **Dementia Screening Programme** in rural **KenYa** (DEM-SKY), an approach aimed at using Community Health Workers to increase the dementia screening rates within the region and promote the timely diagnosis of dementia, without disrupting current health care systems.

Informal health providers such as Community Health Workers (CHWs) play a key role in the continuum of care process. They are able to articulate the needs of the communities and mobilize resources that are salient in decision-making and service delivery processes [7]. The shortage of health care staff in Kenya reveals constrained health systems which may struggle to meet the increasing disease burden unless a comprehensive and collaborative approach is used to address uncoordinated pathways to dementia care. Strengthening a community-level health system using a multidisciplinary approach could provide an opportunity for development of a responsive environment for timely dementia diagnosis in clinical settings [8].

The local team's experience has revealed that with training, primary health care providers in Kenya can collaborate with community health providers [9] to improve screening for priority mental health conditions [10–13].

The locality of the implementation of the region (Makueni County, Kenya) has been selected for multiple reasons. First, it represents a location in which dementia screening is not common practice. Second, the demographics of the region represent poverty and literacy levels below the national average [14,15], which can be contributors to people not being screened for dementia. Third, we have existing connections with clinical staff in the region. Finally, as part of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project, the local CHWs have already received a dementia awareness and anti-stigma training. As such, the CHWs have the knowledge about the importance of receiving a diagnosis and this project will provide these CHWs the tools to facilitate this.

This is the first community-level intervention to integrate dementia screening within Sub-Saharan Africa. Whilst geographically close countries (e.g., Uganda [16]) have adopted screening tools as a means to estimate prevalence, the proposed programme involves using existing human resources (CHWs) to generate new pathways for a formal diagnosis. Due to the novelty of the community dementia screening within the region, this project primarily seeks to understand the implementation of such a programme. At present, it is unclear what are the barriers and facilitators of such a screening programme within LMICs, and therefore how best to ensure successful adoption. The information provided in this paper will be beneficial to researchers, clinicians and policy makers in other LMICs be able to replicate the programme and to provide transparency in its evaluation.

In this protocol paper, we describe the steps and processes (e.g., research design, procedures, outcomes, analysis, stakeholder engagement and ethical considerations) we will employ to

implement the DEM-SKY intervention in rural Kenya to promote replication in similar settings.

PROJECT DESCRIPTION

The primary purpose of this project is to implement a comprehensive, yet pragmatic dementia screening tool within rural Kenya. The project will increase the dementia screening rates within the region, without disrupting current health care systems. This will be achieved by redeploying and training existing volunteer staff (CHWs) to lead the dementia screening. The integration of a process evaluation framework will help identify the barriers and facilitators of successful adoption of such dementia screening in other settings.

See Appendix A for the programme description of DEM-SKY.

METHODOLOGY

In adopting a process evaluation framework within this programme, it will help identify factors that facilitate or hamper the successful adoption of dementia screening within the rural Kenyan context. An evaluation of its implementation can help facilitate our understanding and contextualise why dementia screening and diagnosis rates do (or do not) increase during the project. We have adopted a process evaluation framework, as described elsewhere [17,18], to understand how the intervention unfolded, its internal dynamics and the factors that influenced implementation [19]. We aim to evaluate the following domains: Recruitment, Reach, Dose delivered, Dose received, Fidelity, Satisfaction, Maintenance, and Context.

PROCEDURE

Ten CHWs attached to Makueni County Referral Hospital will be provided the skills and resources required to deliver dementia screening within the community. We will deliver training to the CHWs on how to screen for dementia, the pros and cons of screening, and how to talk about the screening outcome to older adults. Relevant hospital staff at Makueni County Referral Hospital will also be trained on the dementia screening tools, so they understand what screening positive means for their clinical practice. However, the hospital staff will be informed that they do not have to deviate from their normal clinical practice (e.g., they do not have to prioritise or alter diagnostic processes for patients who screen positive).

CHWs will be provided the means (e.g., tablet/paperwork with screening measure) to complete the screening process for individuals over the age of 60 years old within their community. The CHWs will approach older adults on an ad-hoc basis, though monthly meetings with the research team and hospital staff may guide more purposeful screening (described below).

Conceptually, we are agnostic to the optimum tool to screen for dementia. Whilst there are a multitude of dementia screening tools, each with their own pros and cons, we were driven by implementation and feasibility aspects. First, any tool needs to be completed by non-clinicians to allow it to be delivered by CHWs (e.g., validated screening tools such as the General Practitioner Assessment of Cognition (GPCOG) would not be appropriate as it was developed for use by medical professionals [20]). Second, any tool needs to be culturally and educationally fair. Finally, we recognise that shorter tools are likely to be more palatable to older adults, but also increases the likelihood of adoption by policy makers and healthcare providers long-term. We opted to trial a validated screening tool:

1. The Brief CSI-D [21] is a short dementia screening tool for use in by non-specialists in resource poor settings. The tool benefits from being very short to administer (e.g., 10 minutes long). The tool has been utilised within other countries within Africa such as Uganda [16], Nigeria [21] and South Africa [22].

The Brief CSI-D measure will be translated and delivered into the local language (Kamba), utilizing a process of forward and backward translation, followed by reconciliation.

After completing one of the screening tools, the algorithm will highlight those who potentially have dementia (based on the Brief CSI-D), and the CHWs will inform the older adult what this means. Importantly, the CHWs will provide a referral letter for the older adult to the local hospital (Makueni County Referral Hospital).

Anonymous data (refusals, number of people screened and those who screen positive for dementia) will be shared during the pre-existing monthly meetings held between the CHWs and the public health officer to feed into the hospital registry for reporting. These monthly meetings also provide an opportunity for CHWs to share challenges and tangential community health needs. These meeting will allow for the public health officer to guide future recruitment targets in line with local priorities (e.g., geographic regions). DEM-SKY is not about developing parallel and/or new services systems but to use existing health system approaches and resources to generate evidence and increase access to support among older adults.

See Appendix B for the further description about the delivery of DEM-SKY.

PARTICIPANTS

There will be four levels of participants to effectively evaluate DEM-SKY:

- 1) Older adults (n≈2,400). All older adults will need to be over the age of 60 and living in Makueni County. Participants will require an informant (a friend or family member) who is also willing to participate.
- 2) The CHWs (n≈10). CHWs will be required to be affiliated with Makueni County Referral Hospital. Only CHWs who receive training to deliver the dementia screening will be included.
- 3) The researchers (n=2) involved in the delivery of training.
- 4) Hospital staff (n= 10) (e.g., psychiatrist, medical officers, clinical officers, psychologists, social workers, mental health nurses). Hospital staff will be based at Makueni County Referral Hospital and will be responsible (directly or indirectly) for the assessment, diagnosis and treatment of people with dementia.

MEASURES

The rationale for outcomes will be to support the evaluation of DEM-SKY. See Appendix C to see how the outcomes align with process evaluation [17] and RE-AIM frameworks [23].

AUDIT

Throughout the study we will collect data derived from a variety of sources to monitor the numbers of people that have been approached, screened, and formally diagnosed with dementia. For the purposes of this protocol, these fall under classification of “audit” data. Researchers will engage with the Makueni County Referral Hospital to extract pertinent anonymised data from primary care medical records. These data will include the number of people diagnosed with dementia during the implementation period (6 months), but also historic numbers. We will not gather these audit data after the implementation period has ended.

QUESTIONNAIRES

Embedded within the screening tools, there will be a series of additional questions aimed at older adults and CHWs. These questionnaires are designed to better understand who, where and how the dementia screening is being implemented. These include:

1. Older adult characteristics– age, sex, ethnicity, subjective socioeconomic status (MacArthur Scale of Subjective Social Status), loneliness (Three-item loneliness scale)[24], wellbeing (EUROHIS)[25], literacy, employment status, geographic region.
2. Post-screening satisfaction questionnaire aimed at the older adult (to be completed after every older adult screening):
 - Perceived accuracy of screening outcome.
 - A series of behavioural intention questions related to the likelihood of speaking to a doctor, friends and family about the outcome of the dementia screening (1- Very Likely to 4 = Very Unlikely)
 - Three items adapted from the Acceptability of Intervention Measure (AIM)[26].
 - Perceived length of the screening process (1= Much too long to 7= Much too short)
3. Post-screening questionnaire aimed at the CHW (to be completed after every older adult screening):
 - Deviation from training related to dementia screening
 - Confidence in data
 - Perceived accuracy of dementia screening
4. Refusals, with reasons (if provided).

QUALITATIVE OUTCOMES

Qualitative research methods will be used across four participant levels to understand opinions about the dementia screening implementation:

- 1) Hospital staff will be invited to participate in individual interviews at the end of the implementation period. Interviews will focus on understanding their thoughts about the dementia screening programme and changes in practice as a result of the programme.
- 2) CHWs will be invited to focus group discussions at the end of the implementation period to understand the satisfaction and experiences of staff in delivering the dementia screening programme.
- 3) Researchers involved in the delivery of the training of CHWs will be invited to participate in individual interviews to understand how the training went and any issues related to the delivery.
- 4) A subset of older adults (n=22) will be approached following their dementia screening. Half of participants will be selected on the basis of screening positive. They will be asked about their views on the dementia process and its outcome. We will also explore whether screening positive will influence any of their health behaviours in the future.

ANALYSIS

As a pragmatic implementation programme, there is not *a priori* sample size calculation. Descriptive data of those who participated in the dementia screening programme over six months will be reported. However, logistic regression models will be used to understand the factors that influence participation in the screening, completeness of data, as well as those

who screen positive for dementia. We will report the number of people that Makueni County Referral Hospital see for dementia and the numbers that go onto receive a diagnosis during the implementation period (6 months). These monthly rates will be compared to historic rates prior to the screening programme.

An applied thematic analysis approach [27] will be adopted to better understand CHWs experiences and opinions of the dementia screening programme. Coding and theme development will be inductive in nature by multiple researchers, but interpretation will be driven in part by the underlying process evaluation framework. Theme generation will be collaborative and reflexive, acknowledging that researchers will have different experiences, backgrounds and interpretations of the qualitative data. Qualitative interviews with hospital staff and older adults will provide complementary perspectives, but also act as a means of triangulation. Interviews with the researchers who delivered the dementia screening training, will be reported descriptively as a reflective practice report.

As part of secondary analysis, we will report on some of the psychometrics properties for the Brief CSI-D screening algorithm.

KEY STAKEHOLDER ENGAGEMENT

We understand the importance of public or patient involvement to ensure that the research and its outcomes remain meaningful to local communities. EM (Co-investigator and person with lived experience caring for someone with dementia) will facilitate engagement via the Alzheimer's and Dementia Organization, Kenya (ADOK), with relevant stakeholders. These stakeholders will include older adults, people with dementia, carers and policy makers. ADOK and stakeholder engagement will help inform the interpretation of findings and dissemination strategies.

ETHICAL CONSIDERATIONS

Ethical approvals have been sought and granted through Maseno University Scientific and Ethics Review Committee, Kenya (reference number: MUSERC/01102/22).

In adherence with the principle of a person-centred care and a timely diagnosis, we will adopt the philosophy that it is the older adults' choice to receive dementia screening and/or a diagnosis. Enforcing dementia screening may also not be palatable to the general public or clinicians [28]. As such, there may be some older adults who refuse to be screened or refuse to access the primary care team following a screen positive. All older adults will be informed about the benefits and disadvantages of screening for dementia and consent will be obtained.

DISCUSSION

DEM-SKY sets to implement a novel dementia screening programme within Makueni County, Kenya. The programme will develop linguistic and culturally relevant tools, to allow for dementia screening to occur both within this study and in the future. Importantly, the study will highlight barriers and facilitators to implementation, whilst comprehensively describing the context to which the screening occurred. The evidence generated will permit future policy makers, clinicians and researchers to understand, adopt and adapt the programme within other contexts.

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DATA AVAILABILITY STATEMENT

There is no data associated with this manuscript.

CONFLICT OF INTEREST:

The authors report no conflicts of interest

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