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Christine W. Musyimi *Africa Mental Health Training and Research Foundation*

Levi A. Muyela *Africa Mental Health Training and Research Foundation*

David M. Ndetei *Africa Mental Health Training and Research Foundation*

Sara Evans-Lacko *The London School of Economics and Political Science*

Nicolas Farina *Peninsula Medical School*

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# Title: Acceptability and feasibility of a community dementia stigma reduction programme in Kenya

Christine W. **Musyimi**[a], Levi A. **Muyela**[a], David M. **Ndetei**[a,b], Sara **Evans-Lacko**[c], Nicolas **Farina**[d]

1. Africa Mental Health Research and Training Foundation, Nairobi, Kenya.
2. University of Nairobi, Nairobi, Kenya.
3. London School of Economics and Political Science, London, United Kingdom.
4. University of Plymouth, Plymouth, England.

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**Corresponding author**: Dr. Christine Wayua Musyimi

Postal address: 48423-00100, Nairobi. Kenya;

Telephone: +254202716315

Email address: christine.musyimi@amhf.or.ke

**Abstract**

**Background:** Dementia stigma has adverse effects on people with dementia and their carers. These effects can lead to poor quality of life among other negative impacts.

**Objective**: The aim of this study is to develop and pilot a novel dementia stigma reduction intervention in rural Kenya, leveraging existing Community Health Workers (CHWs) for its delivery.

**Methods:** The pre-post pilot study was conducted, utilizing a parallel mixed-methods design. Ten CHWs were trained to deliver a contextually developed dementia anti-stigma intervention. These CHWs delivered four workshops to 59 members of the general public in Makueni County, each workshop lasted between 1.5 to 2 hours. Focus group discussions and pre/post surveys were used as measures.

**Results**: The intervention was well received amongst the participants, particularly in terms of its format and accessibility. We observed the largest effects in reducing negative beliefs related to treatment ($\eta 2 = 0.34$), living well with dementia ($\eta 2 = 0.98$) and care ($\eta 2 = 0.56$) for the general public post intervention. Improvements to attitudes were also observed in the CHWs, but the effect sizes were typically smaller.

**Conclusion**: The intervention was accessible and feasible in rural Kenya, whilst also showing preliminary benefits to stigma related outcomes. The findings indicate that culturally sensitive interventions can be delivered in a pragmatic and context specific manner, thus filling an important knowledge gap in addressing stigma in low-resource settings. Future research is needed to ascertain the intervention’s long-term benefits and whether it tackles important behavioral outcomes and beliefs deeply ingrained within communities.

**Key words**: Dementia, Alzheimer's disease, anti-stigma, intervention, general public, feasibility

## Background

Dementia stigma negatively affects the health and quality of life of those living with the condition and their carers [1]. It can also act as a barrier to seek information, care and support [2,3]. Dementia stigma can be conceptualized in several ways, based on who perpetrates it and the nature in which it occurs [2,4]. For example, public stigma typically relates to the stereotypes, prejudice and discrimination that members of the general public enact on people with the condition [5]. A consequence of public stigma can be social exclusion [4], in which people with dementia are denied public participation or distanced due to beliefs that people with dementia are incompetent or unpredictable[4,6]. In addition to public stigma, people with dementia and their carers may also experience other types of stigma including stigma by association (e.g., stigma attached to those associated with the person with dementia such as a carer) and self-stigma (e.g., people with dementia internalising public stigma) [7]. Models of stigma recognise the importance of cultural norms in shaping how stigma presents itself [8,9].

Approximately 258,000 older adults in Kenya are potentially living with dementia [10]. Generally, the number is expected to rise to 361,000 by the year 2050, a 316% increase since 2019 [11]. Despite the growing numbers of people with dementia, not a lot is known about how dementia stigma manifests in Kenya. Whilst we can infer common patterns from other countries, very little exists on dementia stigma in Africa in general [12]. In one of the only studies in the region, it was found that dementia was often believed to result from being bewitched or cursed, and that through spirituality dementia outcomes can be improved [13]. Dementia was also commonly attributed to normal ageing or 'falling from grace' —in that, one who previously assumed a high social status has now lost it [13]. Depending on the belief held, people with dementia are either be seen as being punished or not in need of formal support. It is unsurprising that these beliefs can have a negative effect on health-seeking behaviour [14], and amplify the challenges of living with dementia.

There are well established models of reducing stigma that typically encompasses education and contact [15]. Despite the highlighted impacts of dementia stigma and pathways to change, there is a dearth of interventions primarily aimed at reducing stigma in Low- and Middle-Income Countries (LMICs) such as Kenya. As of 2019, there was not a single stigma reduction intervention related to dementia outside of the US, Canada, UK and Australia [16]. Only recently has a protocol for dementia stigma reduction in Brazil been published [17], albeit aimed at healthcare staff. There is an apparent lag behind mental health stigma reduction interventions which appear to be growing in number and quality [18]. However, even within the mental health stigma field there is scope for improvement, with the majority of interventions not considering cultural values and context [5,18,19]. Developing dementia stigma reduction interventions that are culturally specific and fit within the local context is essential to ensure they are relevant, acceptable and effective to the context and participants.

The aim of this study is to develop and pilot a novel dementia stigma reduction intervention in rural Kenya, leveraging existing Community Health Workers (CHWs) for its delivery. In this study we evaluate the acceptability and feasibility of the intervention on dementia stigma reduction.

## Methods

### *Context*

The research occurred within Makueni County in rural Kenya with a population of about one million. It is one of the counties whose residents greatly attribute dementia and other mental illnesses to witchcraft resulting in limited access to timely diagnosis and care [13,20].

The government of Kenya through the Ministry of Health has enabled the recruitment of CHWs who work within community health units and are attached to a health facility. Each CHW is attached to 20-100 households and is in charge of the delivery of basic health services including health promotion [21]. The CHWs report to Community Health Assistants who are answerable to the Community Public Officer or Nurse under the title 'community health extension worker' [22]. CHWs are often chosen to deliver public health interventions to the community since they are easily accessible to the community members and are well endowed with the knowledge of appropriate referral systems in the event that there is a condition that requires further medical examination or care [22]. They have been shown to be effective in delivering behaviour change interventions especially in situations where there is paucity of healthcare workers [21].

### *Intervention*

The development of the anti-stigma intervention followed the Medical Research Council (MRC) framework for development of complex interventions comprising four phases [23]. In each of the phases, key considerations were made such as relevant stakeholder engagement throughout the development process and dynamic iterative processes to intervention development [24]. Further details of the development process are in Appendix A.

The final intervention took the form of a train-the-trainer programme, in which individuals without formal education receive training on a given topic and instructions on how to train others on the approach [25]. Within the context of this study, we delivered training to ten CHWs to promote awareness and reduce dementia stigma. Content included promoting understanding of dementia, demystifying myths and misconceptions and promoting social inclusion through a case vignette and discussions (figure 1). Videos of people living with dementia and carers were used as the social contact element of the intervention—an empirical and important element of anti-stigma interventions [26]. The CHWs were also given guidance on how to deliver a similar session to members of the general public [27].

Pairs of CHWs were then asked to deliver and facilitate stigma reduction workshops with the general public. CHWs delivered four group workshops (composed of 10-12 adults, which included people of different ages and different experiences of dementia), over a two-week period. Each workshop lasted between 1.5 to 2 hours.

The intervention can be found here: https://stride-dementia.org/wp-content/uploads/2022/07/STRIDE_Intervention_Kenya.pdf

### *Design*

The pre-post study was conducted, utilizing a parallel mixed-methods design.

### Procedures

Participants included a pragmatic sample of ten CHWs (within the study site) and members of the general public involved in the intervention. The members of the general public were recruited by the

CHWs through convenience sampling, inviting adults (18 years and older) in the community during the CHW's usual role. However; the research team asked the CHWs to identify a broad sociodemographic representation (e.g., diverse age, gender, social status, and experience of dementia). Participants were required to be over the age of 18 years old and provide informed consent to participate in the research. Information was provided to the participants prior to the study and they were provided with an opportunity to ask any questions before choosing to participate. CHWs and members of the general public were informed that they would be involved in the intervention.

For CHWs, questionnaires about knowledge and beliefs surrounding dementia were collected prior to their first training session and then within one month after delivering the stigma reduction workshops. For the general public, the same questionnaires were asked prior to their first stigma reduction workshop and then one month after the workshop. A subset of participants were invited to participate in focus group discussions (FGDs) to understand their experiences and opinions of the intervention. Six FGDs (two FGDs with CHWs and four FGDs with members of the general public who received the intervention) were conducted within one month of the intervention being delivered by the CHWs. The participants of the six focused groups were chosen based on the following categories; CHWs, carers of people with dementia, people with a relative with dementia, people who do not have a relative with dementia and a mixed group of people with relatives and those without relatives living with dementia. The selection of participants for the FGDs was based on convenience (degree of participation during intervention delivery and availability). FGDs were led by a female Kenyan dementia researcher (CM), audio-taped and lasted between 60 and 90 minutes. All the training, intervention material and questionnaires were delivered in Kamba (one of the local languages in Kenya).

## Measures

Socio-demographic questionnaire: This included information on age, gender, education, religion and employment.

Alzheimer's Disease International (ADI) global questionnaire on dementia stigma: This questionnaire was adapted from the World Alzheimer's Report (WAR) through public engagement and input from the research team and covers knowledge, attitudes and behavioural intention, and has been tested among 70,000 people in 155 countries [2]. In the current study, there were some edits to the statements (e.g., clarifying that nursing home could also mean residential care homes, and removing questions that were overly scientific (e.g., presence of apolipoprotein E (APOE) and high levels of norepinephrine). This is because participants generally had lower levels of education and some of these terms were new to participants during adaptation. The adapted version included 91-items that measured knowledge (i.e., causal attribution of dementia) alongside attitudes and beliefs related to: (i) treatment, institutional care and safety, (ii) social distance, (iii) personal risk, (iv) secrecy, (v) help-seeking, (vi) health care worker stigma, (vii) anticipated stigma, (viii) resource allocation, and (ix) structural stigma. All item responses were provided on a Likert scale.

The interview guides, developed by the research team included open-ended questions covering challenges and motivations of participants to engage in the training, intervention appraisal, knowledge acquisition and its application following training.

## Analysis

Descriptive statistics (mean and standard deviation; frequency and percentage) were reported for participant sociodemographic information. These were reported separately for the general public and CHWs.

Perceived aetiology of dementia was reported descriptively at each time point (i.e., frequencies, percentages) for the general public and CHWs. For general public data, a Wilcoxon analysis was completed on items between time points. For the purpose of this between time point, nominal analysis we excluded “don’t know” responses. To facilitate interpretation of the 5-point Likert scales we dichotomised outcomes into affirmative (Very likely and Likely) and non-affirmative responses (Not likely and Not at all likely), excluding “don’t know”.

Belief items were conceptually grouped into themes (see Appendix B), namely, beliefs about risk (k=3), treatment (k=4), living with dementia (k=9), care (k=5), and secrecy (k=8). Individual items were reverse coded so that all items could be interpreted consistently (e.g., 5 represents more negative beliefs). Items within each theme were summed, responses with missing data or “don’t know” were excluded. Repeated measure ANOVA was used to understand the difference between time points, with an effect size reported (partial eta squared). Partial eta squared was used as standardised means to compare change, as a guide η2 = 0.01 indicates a small effect, η2 = 0.06 indicates a medium effect, and η2 = 0.14 indicates a large effect size. The analysis was replicated for the general public and CHWs separately.

To evaluate the nature of missing data within the beliefs data at baseline and follow-up, Little's MCAR test was employed. A p-value less than 0.05 on the test indicates that the data were not missing at random. If data were missing at random, we repeated the main analysis following mean imputation in cases where there were less than 50% missing items within a belief theme. The belief data at baseline (General public, Little’s MCAR = 0.25; CHWs, Little’s MCAR = 1.00) and follow-up (General public, Little’s MCAR = 0.16; CHWs, Little’s MCAR = 1.00) were considered missing at random.

For FGDs, audio files were transcribed and translated to English for analysis. Inductive thematic analysis was adopted, to ensure that interpretation is data-driven to that we do not miss any unexpected themes by trying to fit it into a pre-existing coding frame[28]. Researchers (CM and LM) coded the transcripts. The scripts were initially reviewed independently, and a meeting followed to agree on a coding framework. The researchers then coded the scripts independently and met to review the different codes. These codes were subsequently grouped into subthemes and themes, based on commonality. Whilst CM conducted the interviews and formed part of the analysis team, she remained cognizant of any personal views that may affect the analysis to ensure that themes emerged from the data. Specifically, we adopted a pragmatic standpoint as an epistemological perspective, to better allow us to seek practical insights into the stigma reduction intervention.

Quantitative analysis was performed on SPSS (version 25) whilst qualitative analysis was performed using NVivo 12[29,30].

## Results

Fifty-nine members of the general public and 10 CHWs participated in the anti-stigma intervention pilot evaluation. The general public were aged between 21 and 73 years old, and 57.6% were female (n=34). Six participants (10.2%) had never heard of the terms “dementia” or “Alzheimer’s disease”. The CHWs were aged between 41 and 61 years, and predominantly female (n=7, 70%). All CHWs had heard of “dementia” and/or “Alzheimer’s disease”. See Table 1.

Four participants from the general public (6.7%) did not complete the follow-up questionnaire. Those who did not complete the follow-up questionnaire did not significantly differ from the rest of the sample based on age (MD= -8.82, p=0.25), sex (χ2 = 1.87, p=0.30), educational attainment (χ2 = 1.55, p=0.82), or whether they had heard of dementia before (χ2 = 7.69, p=0.05). There were no dropouts between timepoints for CHWs.

### *Attitudes*

***General Public:*** One month post intervention, there was a statistically significant reduction in negative beliefs related to risk (p=0.04), treatment (p<0.001), living well with dementia (p<0.001), care (p<0.001) and secrecy (p=0.03). See Table 2. Following mean imputation across themes (where there was less than 50% data missing), the same direction of effects was reported. See Appendix C.

***Community Health Workers:*** Following the programme, the CHWs had improved beliefs across all domains. However, only beliefs about treatment had a large enough effect to be statistically significant (ηp2=0.60, p=0.01). See Table 2 and Appendix E.

### *Causal attribution*

***General Public:*** At baseline, the most frequent affirmative response to the causal attribution of dementia was brain disease (n=55; 93.2%), normal aging (n=49; 83.1%) and brain injury (n=44; 74.6%). Witchcraft received the fewest affirmative responses (n=7; 11.9%). Following the intervention, the most frequent affirmative responses were brain disease (n=51; 86.4%), unhealthy lifestyle (n=43; 72.9%) and lack of family support (n=43; 72.9%). Again, witchcraft was the least frequently reported aetiology with an affirmative response (n=9; 15.3%). See Appendix D. Non-parametric paired analysis revealed that the general public's knowledge surrounding the aetiology of dementia did not significantly change between timepoints (p>0.05); the one exception being that participants at follow-up were more likely to believe that dementia is due to a lack of family support (Z=-3.61, p<0.001).

***Community Health Workers:*** At baseline, the predominant causal attribution for dementia amongst CHWs was brain disease, with 90.0% of respondents (n=9) affirming this belief. The next most common attribution was that it was caused by head or brain injury (n=7; 70.0%) and lack of family support (n=7; 70%). 60% (n=6) also believed dementia was a normal part of aging. Although receiving one of the lowest affirmative responses, 20% (n=2) of CHWs believed that dementia was due to witchcraft. At follow-up, 100% (n=10) of participants attributed dementia to being a brain disease, though 90% of CHWs (n=9) believed that dementia was due normal aging. One CHW (10.0%) still responded affirmatively to the statement that dementia is due to witchcraft at follow-up, despite also believing that dementia was a brain disease. See Appendix D.

## Qualitative Results

Thematic analysis identified four overarching themes: 1) positive aspects of delivery, 2) challenges to delivery, 3) motivators to participation, and 4) perceived efficacy.

### *Theme 1: Positive aspects of delivery*

The first theme was related to the perceived positive aspects of delivery. Within this theme, we grouped codes that related to positive feedback surrounding how the intervention was delivered and highlight four subthemes; group working, inclusivity, accessible, and positive relationships with the trainer.

***Group working:*** Most participants described the group setting as the most conducive set up rather than individualized sessions since they would learn from each other through interactions and get different perspectives through the discussions. See Table 3, section A1.

***Inclusivity:*** Participants also preferred the diversity in the formation of the groups as it included representatives from different ages, providing a unique opportunity for broader reach and sharing experiences across various ages.  CHWs were also able to identify that by being inclusive could allow the general public to support one another. One example provided was how literate participants could support illiterate participants in contributing to some elements of the workshop.  See Table 3, section A2.

***Accessible:*** Participants praised the accessible nature of the workshops, most notably by using language that was understandable. This included using simple terminology and the local language rather than English during the workshops. See Table 3, section A3.

***Positive relationships with trainer:*** Overall, the general public felt that the trainers were well trained, and there was broad positivity towards them. Some did acknowledge that the trainers (as CHWs) were already known to them, and thus the workshops built upon existing relationships.  See Table 3, section A4. Within these subthemes, there was also the view that the trainers respected their time, which made them to feel valued (Table 3, section A4).

### *Theme 2: Motivation*

The second theme was related to the motivators of participating in the intervention.

***Acquisition of knowledge:*** This was a common subtheme mentioned as a motivating factor for attending the training. There appeared to be a general desire to learn about the condition, without other motivations (see lived experience subtheme). Typically, they acknowledged that they did not know much about dementia beforehand.  CHWs also reported to have observed this desire to learn. See Table 3, section C1.

C***ommunity benefit:*** For CHWs, due to their job role in serving the community, they saw how attending the training would benefit the community as a whole. See Table 3, section C2.

***Lived experiences:*** For some participants, they described past experiences of seeing neglect, isolation and mental health issues for people living with dementia and did not know how to offer any care and support. As such, participants felt that this was an opportunity to learn these skills to help similar people in the future. See Table 3, section C3.

### *Theme 3: Perceived efficacy*

Both the general public and the CHWs recognized the value of the intervention, and in particular commented on how they felt it improved their knowledge and skills.

***Improved knowledge and skills:*** Participants were able to reflect on knowledge gained from the intervention and describe how their knowledge and behavior had changed compared to before the intervention.  Subjectively, both the general public and the CHWs reported improvements. See Table 3, Section C1.

### *Theme 4: Improvements to intervention delivery*

Participants were also able to identify areas for improvement, or perceived challenges in the way that the intervention was delivered.

***Access to materials:*** Participants expressed a desire to have their own training materials to aid them during the training process. They preferred to have them in order to follow the trainer through the session as well as a tool for educating others after the intervention was over. These materials would also serve as reminders during the recapitulation portion of the session as reported by some participants. See Table 3 section D1.

***Broader reach:*** Some participants were aware of others that wanted to attend the workshop but were unable due to logistical constraints.  CHWs also recognized a desire for others to attend. However, the CHWs identified that due to the centralized nature of the workshops, it prevented people from attending due to lack of transport. See Table 3 section D2.

## Discussion

This is the first dementia stigma reduction intervention piloted in Kenya.  Our findings indicate that our novel, CHW-led intervention, was well received amongst both the CHWs and the general public, thus building upon previous evidence highlighting how community health providers can have a role in engaging with communities in rural areas and LMICs [31–33]. Preliminary evidence also suggest that the intervention would potentially have an impact in reducing some domains of dementia stigma.

There were several perceived strengths of the intervention, including the adoption of group working, its inclusiveness, and the positive relationships with the trainers. Importantly, the findings indicate that participants saw the intervention as being accessible, praising the terminology used and the adoption of the local Kamba language for its delivery.  It is positive to that our efforts to tailor the intervention were reflected in this feedback. Within Kenya, 38.5% of adults are illiterate [34], and whilst English and Swahili are official languages of Kenya, Kamba is typically the primary language of the Akamba community who make up 97% of Makueni County [35].  Although tailoring content to the target audience seems common sense, this is not always achieved. For example, within the UK, only 24.3% of evaluated patient leaflets met recommended reading criteria [36].

FGDs did identify that the interventions had scope for improvement, if additional reading material related to the content was provided. Such information would allow provide opportunities for the general public to engage with the topic before, during, and after the workshops.  We can draw upon learning models, such as constructivism [37], where information booklets could help people better achieve self-directed learning. Creation of such a resource would have a cost, particularly if we wanted to ensure that the content was accessible.

Following the intervention, attitudes and beliefs surrounding treatment, care and living with dementia demonstrated the largest positive effects amongst the general public. These findings were robust following imputation and aligned with subjective reports about how the intervention improved knowledge. Improved beliefs surrounding risk factors were observed following the intervention, but the effects were more modest before (ηp2 =0.14) and after imputation (ηp2 =0.07). In line with these findings, the majority of knowledge surrounding causal attribution did not significantly change following the intervention. Interestingly, the only item to significantly change was more from the general public who stated that lack of family support was a cause of dementia. This shift may be attributable to the intervention's emphasis on the importance of supporting people with dementia. Perhaps an approach to mitigate this in the future would be to further develop the section on family support in order to explain its place in the care of a person with dementia and ultimately demystify the perceived association between family support (as described in our intervention) and dementia etiology.

It should also be noted that content related to risk factors and etiology did not prominently feature within the intervention, outside key messages that dementia is a brain disease and not due to normal aging or witchcraft (two common views in Kenya) [13,20]. The fact that there was still a minority of participants who believed that dementia was caused by witchcraft or just normal aging after the intervention, could indicate that these beliefs are deeply ingrained[38,39]. In fact, considering dementia as part of normal ageing, visiting traditional and faith healers and taking no action have been found to be the initial dementia care pathways following dementia suspicion in rural Kenya [2]. This finding is not unique to our setting as other studies in sub-Saharan Africa have established this pathway as a mechanism sought by people with dementia and their families to manage the condition[39]. Irrespective, there is a case for raising awareness about dementia etiology and risk factors through public health messages as a means to reduce risk of dementia [40] and reduce the existing knowledge gap on causal attribution.

Our findings indicate that despite CHWs receiving the dementia training to be able to deliver the stigma reduction intervention, there were no statistically significant improvement across beliefs and attitudes following imputation. Whilst CHWs were not seen as the primary beneficiaries of the intervention, it is positive that attitudes did not worsen as a result of the intervention even though the majority of CHWs still believed dementia was a normal part of aging. We should reflect that the CHWs were more likely to have heard of both dementia and Alzheimer's disease terms and had more experience of the condition, compared to the general public. In addition, the CHWs had more positive dementia beliefs compared to the general public across majority of outcomes at baseline and follow-up. However, healthcare staff are not immune from holding negative beliefs, particularly in LMICs [2]. Intrinsically, educating healthcare workers may also prove to be beneficial as a way of increasing awareness on dementia [41]. The inclusion of the fact that dementia tends to double after every five years beyond the age of 65 years [42] could have been mistaken as being normal during old age by the CHWs. This reflects an overarching principle defining etiology of dementia that is not specific to our setting as other studies within sub-Saharan Africa have established similar findings [38,39]. As such, there is a need to better clarify the context around this information and distinguish between increased prevalence and the relationship between aging and dementia in future trainings. Considering this is a group that has better knowledge of Alzheimer's disease and dementia, an additional measure would be beneficial to ascertain the change. We recommend using a knowledge, attitudes and practice questionnaire in addition to standardized measures to ascertain change.

### ***Study limitations***

There are several limitations of the study. First, given that this was not a study on the effectiveness of the intervention, we may not make conclusions about the impact of the intervention and therefore statistical significance of the change (or lack thereof) portrayed by our findings, particularly for CHWs and where effect sizes are small. Second, we are only able to comment on the short-term benefits of our stigma reduction intervention. This is a reoccurring issue amongst mental health stigma reduction interventions in LMICs, with the majority only following participants up at the end of the intervention only [18]. The improvements in dementia attitudes, even if short-term are promising, do not guarantee long-term improvements. For example, an anti-stigma intervention (education, contact and education + contact) demonstrated no significant intervention by time effect on dementia stigma immediately after follow-up [43]. The authors did note that that dementia stigma did reduce across interventions, with greater effects being reported after 12 weeks and those with the highest baseline stigma. This perhaps highlights the need to tailor interventions for the target audience considering the preliminary findings drawn from the CHWs group. We also acknowledge that attitude outcomes (rather than causal attribution) improved for the general public and largely remain unchanged for CHWs. Due to the modest sample size, a larger cohort is needed to definitively report on efficacy. Any further development of the intervention will need to iron out potential messaging issues related to the causes of dementia.

Third, the measured outcome of our study primarily relates to knowledge, beliefs and attitudes. As such, our outcomes represent two out of three subtypes of public stigma; misinformation (i.e., knowledge) and prejudice (i.e., attitudes) [5]. This does mean that our findings do not capture discrimination (i.e., behavior), however, some items do relate to imagined behavior (e.g., "If I had dementia, I would encourage my family to keep it a secret"). Capturing behavior can be difficult, particularly when 27.1% of our sample had no experience of someone with dementia. However, as highlighted earlier, hypothetical behavior may not necessarily reflect actual behavior. Fourth, the changes observed here may not necessarily be representative of the wider population. Notably, we envisage that there will be a level of volunteer bias, where certain demographics (e.g., higher education) or people with certain interests (e.g., dementia) are more likely to participate. Although, a specific criteria to recruit those with specific socio-demographic characteristics in the group was indicated prior to recruitment, we also acknowledge a potential bias to the sampling frame as the selection was made by the CHWs, which could mean that they selected participants only well known to them or those active within their community health units. Finally, we did not have a control group, and therefore there it is hard to say with certainty that the effects reported can be directly attributed to the intervention.

## Conclusion

In as much as our study was not fundamentally focused on assessing the gap in knowledge and attitudes towards dementia, it adds onto information relating to the subject matter in similar contexts. It highlights the significant gap pertaining to information on dementia within our communities [44]. This pilot study demonstrates that a CHW-led dementia stigma reduction intervention in rural Kenya is both acceptable and feasible. The findings indicate that culturally sensitive interventions can be delivered in a pragmatic and context specific manner, thus filling an important knowledge gap in LMICs [16] and potentially creating dementia-friendly communities [45]. Future research is needed to ascertain whether the intervention can be scaled up within Kenya, to a wider audience. It is essential for future research to understand whether the benefits are sustainable long-term, and whether it tackles important behavioral outcomes.

## Conflict of Interest

Christine Musyimi PhD, is an Editorial Board Member of this journal but was not involved in the peer-review process of this article nor had access to any information regarding its peer-review.

## Authorship

All authors contributed substantially to the development of this manuscript

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## Data Availability

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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**List of Tables**

Table 1. Baseline demographics reported for general public (n=59) and CHWs (n=10) that participated in the stigma reduction intervention.

| | General Public | | | Community Health Worker | | |
|---|---|---|---|---|---|---|
| | n | % | Mean (SD) | n | % | Mean (SD) |
| **Age** | | | 45.0 (14.73) | | | 48.8 (5.59) |
| **Sex:** Female | 34 | 57.6 | | 7 | 70.0 | |
| **Education level:** Less than primary school | 7 | 10.1 | | 0 | 0.0 | |
| **Employment:** Full-time/Part-time/Self-employed | 34 | 49.3 | | 10 | 100.0 | |
| **Heard of Alzheimer's Disease or dementia** | | | | | | |
| Neither | 6 | 10.2 | | 0 | 0.0 | |
| Only Alzheimer's Disease | 2 | 3.4 | | 1 | 10.0 | |
| Only Dementia | 35 | 59.3 | | 6 | 60.0 | |
| Heard of both | 16 | 27.1 | | 3 | 30.0 | |
| **Religion:** Christian | 59 | 100.0 | | 10 | 100.0 | |
| **Know Someone with dementia*** | | | | | | |
| Immediate family: Yes | 20 | 33.9 | | 3 | 30.0 | |
| Cohabiting partner: Yes | 8 | 13.6 | | 1 | 10.0 | |
| Non-cohabiting partner: Yes | 7 | 11.9 | | 4 | 40.0 | |
| Other family: Yes | 17 | 28.8 | | 4 | 40.0 | |
| Friend: Yes | 10 | 16.9 | | 3 | 30.0 | |
| Acquaintance: Yes | 20 | 33.9 | | 4 | 40.0 | |
| Work Colleague: Yes | 4 | 6.8 | | 1 | 10.0 | |
| No one known: Yes | 16 | 27.1 | | 0 | 0.0 | |

*Multiple response items

Table 2. Attitudes towards dementia pre- and post- the stigma reduction intervention.

| | General Public | | | | | CHWs | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Pre | Post | | | | Pre | Post | | |
| | n | Mean (SD) | Mean (SD) | *Partial eta sq* | p | n | Mean (SD) | Mean (SD) | *Partial eta sq* | p |
| Risk beliefs (↑ negative attitudes) | **31** | **10.35 (2.26)** | **9.19 (2.57)** | **0.14** | **0.04** | 9 | 9.78 (2.49) | 8.33 (2.35) | 0.25 | 0.14 |
| Treatment beliefs (↑ negative attitudes) | **42** | **8.21 (1.59)** | **6.36 (1.92)** | **0.34** | **<0.001** | 8 | **6.88 (0.99)** | **5.63 (0.92)** | **0.57** | **0.02** |
| Living with dementia beliefs (↑negative attitudes) | **33** | **25.85 (4.03)** | **21.61 (3.86)** | **0.98** | **<0.001** | 7 | 23.86 (3.44) | 23.86 (3.93) | 0.00 | 1.00 |
| Care beliefs (↑negative attitudes) | **35** | **15.57 (2.37)** | **12.00 (3.18)** | **0.56** | **<0.001** | 8 | 12.50 (3.51) | 11.75 (3.65) | 0.08 | 0.46 |
| Secrecy (↑ more secrecy) | **35** | **15.17 (4.77)** | **13.11 (3.87)** | **0.14** | **0.03** | 8 | 14.13 (2.10) | 12.50 (4.41) | 0.16 | 0.29 |

Bold text represents statistically significant differences (p<0.05).

Table 3. A summary of themes and subthemes from thematic analysis of Focus Group Discussion transcripts.

| Theme | | Subtheme | Example 1. | Example 2. | Example 3. |
|---|---|---|---|---|---|
| 1. | Positive elements | 1 Group working | *“We learnt well in groups. We would ask questions, and do group discussions, while on one-on-one a person cannot discuss. Therefore, training in groups was a good approach.”*<br>*Male Carer of person with dementia* | *“Learning in groups in my opinion is a good thing. We appreciated that because whenever we got questions and several people responded, we built the capacity of each other. Group training was better compared to one-on-one training.”*<br>*Female Carer of person with dementia* | *“Groups were the best… in group sessions, the participants would discuss in small groups and understand the training content since each would give their views and write down what they agree upon in their groups.”*<br>*Community Health Worker* |
| | | 2 Inclusivity | *“I also appreciated the selection of participants. Some were old, youth and young people. This composition ensured the information would be delivered to all age groups.”* | *“…Those that didn’t know how to write could contribute by talking and others could write [their contributions down].* | |

| | | |
|---|---|---|
| | *Male*<br>*Member of the general public* | *Community Health Worker* |
| 3 Accessible | *"What I liked about the training was the fact that the trainers trained us well. They trained us with the simplicity and language we could understand. This would help us in training others because we understood the training content in basic terms and in our language that we understand."*<br>*Female Member of the Public* | *"What I liked most from the training sessions was the way our trainers delivered the training sessions. They were good trainers, trained us well, and in the language we would understand. In most cases, most training programs are trained in English, and most people don't understand them well. In our case, we were trained in the language we understood too well and each one of us understood."*<br>*Male*<br>*Carer of person with dementia* |

| | | | | | |
|---|---|---|---|---|---|
| | | 4 Positive relationships with trainer | *"I liked our trainers. These are people well known to us."*<br>*Male Member of the general public* | *"I liked the trainers we had. They trained us with a lot of patience. They didn't rush or condemn us. They appreciated our contributions and taught us as was required. Yes, I liked that."*<br>*Male Member of the general public* | *"Our time was valued and well utilized. All of us were adults coming from different homes and the trainers respected our time schedules."*<br>*Female Member of the general public* |
| 2. | Motivators for participation | 1 Acquisition of knowledge | *"What motivated me most to attend the training workshop was when we were told we would be trained on dementia. From my understanding, I thought dementia affects old people only and so I was motivated to go and learn more. I wanted to know if there is cure after diagnosis, if indeed it affected the old* | *I was told that I was going to be trained about dementia. Since I like gaining knowledge, I set out to attend the training so that I could add knowledge and learn more about myself, others or even other topics because all I knew was, I was going to be trained on dementia but the* | *"What I liked most was that when we invited these people and told them that we wanted to train them, they were very eager to learn what we were going to train them on. When we told them it was about Alzheimer's and Dementia, they were very* |

|  |  |  |  |
|---|---|---|---|
|  | *people or I could also be affected, yes; I wanted to learn more.”*<br>*Female Member of the general public* | *details were not shared.*<br>*Female Carer of a person with dementia* | *much willing to know what the disease was. They were so happy because majority of them have people with dementia in their homes and had no idea that they could be taken to hospital and be treated. Others didn’t know how to care and support their people with dementia.”*<br>*Community Health Worker* |
| 2 Community benefit | *Upon attending [the training], I found we were being trained on things that were going on in my community and especially on dementia myths and* |  |  |

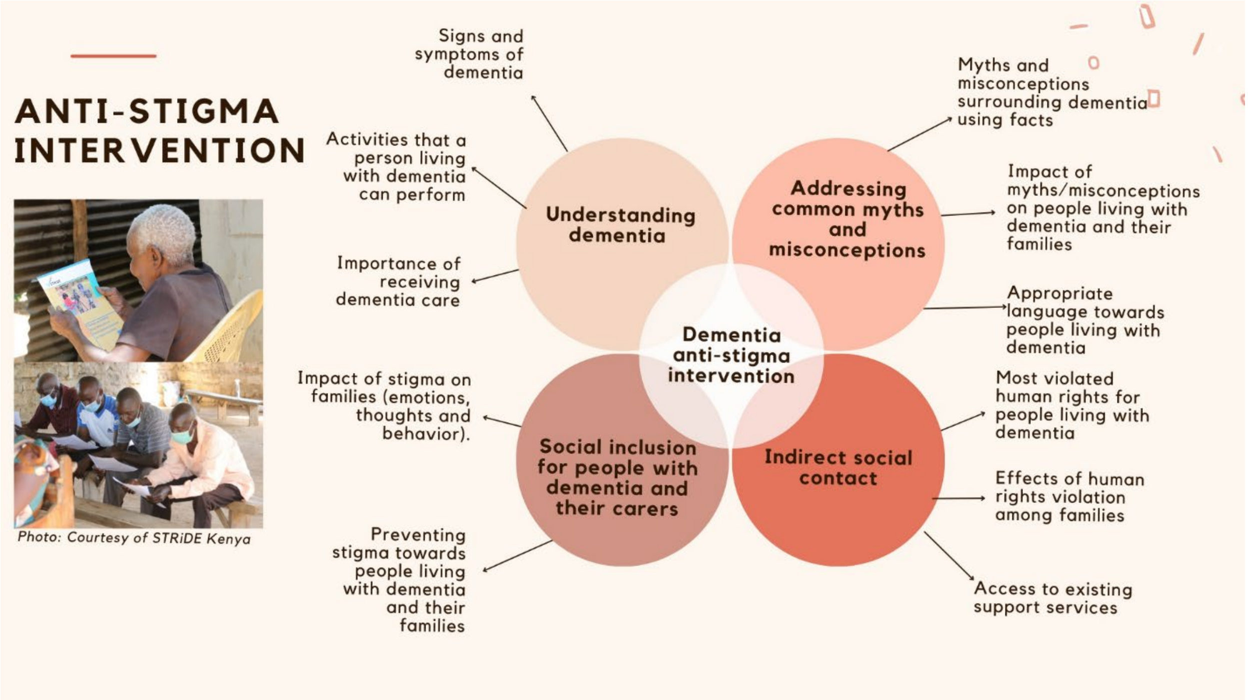
| | | | |
|---|---|---|---|
| | *misconceptions. Therefore, this training helped me and indeed I gained a lot and went back to apply the same to my community so that my people can be helped. I am so grateful to this organization for training me and for myself going to apply gained skills to my community to benefit.*<br>*Community Health Worker* | | |
| 3 Lived experiences | *"[I attended the training] because I have one family member with dementia whom we used to disagree with always. But after the training, I learnt how to relate with him and how to answer his questions whenever he asked."* | *"…there was this woman [with dementia] who was locked in her house. I didn't know how to help her out. I simply visited her home to witness. I found out that the gate is usually locked so that she doesn't get out. Every time there was* | *"I was motivated to attend the training because in my village we have someone with dementia who was always dull [depressed]. People in the village thought he behaved so from inheriting dementia from* |

| | | | | | |
|---|---|---|---|---|---|
| | | | *Female Member of the general public* | *no one at home, this woman would be locked in the home alone. This went on until she eventually died. I thus decided to attend this training to know if there was cure for dementia or what care and support was offered to people living with dementia.”*<br>*Male Member of the general public* | *his family. So, when we were told that we would be trained on dementia, I got interested to learn more. I wanted to learn the signs and symptoms of the condition, how to relate with people with dementia, how to care and support people with dementia and so forth. I thus got interested.”*<br>*Female Member of the general public* |
| 3. | Perceived Efficacy | 1 Improved knowledge and skills | *“One thing that struck me most was that dementia or Alzheimer’s, can get persons of any age group; young and old. Yes,* | *“The trainings are good. I learnt how to communicate with a person living with dementia as well* | *“From our training, the caregivers understood how to care and support someone with* |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  |  |  | *anyone can get this condition.”*<br>*Male Member of the general public*<br>*“I was very happy to learn how to care and support people living with dementia. Honestly, I didn’t know how to care and support people living with dementia. I was glad to learn this.”*<br>*Male Carer of a person with dementia* | *as how to care and support them. I learned new things I didn’t know before the training.”*<br>*Male Carer of a person with dementia* | *dementia. Majority of them changed their approach to people with dementia. [Before] they would shout at someone with dementia, or argue with them. However, many caregivers understood this as a disease that attacks people as well as how to care and support people with dementia.”*<br>*Community Health Worker* |
| 4. | Improvements to delivery | 1 Access to materials | *“I would request if you may find it useful to get us the training materials that were being used to train us. They will be very instrumental in reminding us very* | *“I would appreciate if I was provided with a booklet similar to what the trainers were using. This would help me read in advance.”* | *“One thing I felt would have been useful to my participants was training manuals or leaflets. This would have helped during the trainings so* |

| | | | |
|---|---|---|---|
| | *fast on what we learnt.”*<br>*Male Member of the general public* | *Female Carer of a person with dementia* | *that as we trained, they would be making reference. As we trained, they would be following.”*<br>*Community Health Worker* |
| 2 Broader reach | *…they might not attend the training due to lack of transport facilitation to the training venue. Where people have no transport facilitation, they cannot attend the training. Yes, they could be interested in coming but they don’t have the resources. They have minimal income.”*<br>*Community Health Worker* | | |

**Figure 1: Dementia Anti-Stigma Intervention (DASI)**



*Consent was obtained from all featured participants*

## Appendix A

### Development of the intervention (Medical Research Council Framework)

Recent research revealed discriminative perceptions towards people with dementia and their carers in Kenya. This led to determining the presence and utilization of anti-stigma interventions, if any, and their effectiveness within our context. The process involved reviewing existing research evidence on dementia anti-stigma interventions and theories, supplemented by qualitative interviews with key stakeholders. A recent review found only 21 stigma reduction interventions of dementia from high income countries with none in LMICs, yet local culture is an important component in addressing stigmatizing beliefs [1]. In addition, we determined that there was a dearth in awareness on dementia as a condition and the causal attribution was skewed at best. In order to fill the gap established, the Health Stigma and Discrimination Framework was used to identify the areas to intervene that affect the wellbeing of people with dementia such as human rights and addressing myths and misconceptions since stigma manifests through various practices or negative societal beliefs [2].

We purposed to understand the context where the intervention would be implemented which would in turn inform the content of our intervention. This was performed through conducting qualitative interviews with various stakeholders ranging from clinicians, Community Health Workers (CHWs), members of the general public and people with lived experience (carers of people living with dementia). Interviews revealed lack of knowledge on dementia and its aetiology. There was negative use of the term dementia, attribution of dementia to witchcraft, being cursed and delayed diagnostic pathway due to stigma and neglect [3]. We identified target areas of our intervention which were creation of awareness on dementia, common myths and misconceptions on dementia rights and responsibilities of people with dementia and added a social contact element as a core element of anti-stigma interventions.

From these findings, the initial draft was developed and consisted of four sessions (as shown in figure 1) with one of the sessions integrating an indirect social contact element (videos) to allow people living with dementia and carers to share their recovery-journey experiences in order to promote healthcare access and improve diagnosis rates.  Other aspects included promoting understanding of dementia, demystifying myths and misconceptions and promoting social inclusion through a case vignette and discussions (see figure 1).

### *Feasibility of the intervention*

The developed manual was shared with a sub-set of carers of people living with dementia, clinicians, CHWs and members of the general public to comment on language flow, order, appropriateness of content and any provide any additions. The draft intervention underwent a rigorous review process for a period of one week. This refinement process involved making a presentation of each session and asking participants to post notes or provide thoughts on each session. The manual was also shared with dementia researchers and psychologists who provided edits to make sure that the content focused on reducing stigma rather than providing patient-care related interventions provided at the hospital. Some participants felt that including diet, exercise and other lifestyle factors are influential to address risk-reduction efforts, while others considered these suggestions as not a mandatory component to reduce stigma. After further discussions, participants agreed that diet and exercise can be included as an appendix to provide more information to communities in order to emphasize that “something can be done to prevent dementia”.

### *Implementation of the intervention*

Implementation questions were recorded and responded to throughout the phases to determine the best way to deliver the intervention. These questions were addressed by the; community leaders i.e., spiritual healers, elders within the community and CHWs; the healthcare workers; and the research team. The questions centred around reach and uptake especially due to the perceived complexity of the content of the intervention as this was relatively new information to the study participants. A key component to aid the implementation efforts was the social contact element.

### *Social contact*

This involved video-taping a person with dementia, their carer and family members from the community. The person with dementia gave their story of how they first found out they had dementia and what it was like for the person with dementia. The family members also gave their perspective of what this meant for them and the impact they experienced as a result. They shared how they would prefer to be treated by the community members and expressed the rights of a person with dementia. The video was recorded with the consent of the participants and they were informed that it was to be incorporated into the intervention. We also interviewed a healthcare worker to get his perspective of managing an individual with dementia and added this into the social contact video. In addition to dementia management, the healthcare worker shared on the availability of services to people with dementia.

### *Participants*

The participants were selected from diverse sociodemographic backgrounds to ensure community representation i.e., high and low social class, young and older person, male and female representation and individuals with high and low literacy levels. The preferred deliverers of the intervention were CHWs because they:

1. Have substantial experience in the promotive and preventive aspects of public health within the community.
2. Are a cost-effective way of the delivery of the intervention
3. Have a better understanding of the community members and are trusted by the community

### *Evaluation of the intervention*

We used the Alzheimer's Disease International (ADI) global questionnaire on attitudes to stigma adapted from the World Alzheimer's Report (WAR) to observe change on the participants' knowledge and attitudes with regard to dementia and stigma related to dementia. This was to be administered before and after the intervention by the research team in order to reduce bias. Qualitative assessments were centred around acceptability, delivery of the intervention, number of sessions and areas to improve on among other areas.

Participants were also asked about recruitment and retention strategies, adequacy of the sessions, duration of the intervention and what would make it easier for participants to attend sessions. Weekly or bi-weekly sessions were agreed to be appropriate to ensure that information gained in the previous session is retained, and provide an opportunity for the recipients of the intervention to plan their time to participate in the four sessions within a period of one month. The four sessions were confirmed to be adequate. Participants mentioned that the period between sessions should not exceed one week and each session should be 1-1.5 hours to promote retention.

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**Appendix B**

***Supplementary table 1:*** Items grouped into domains for analysis. Domain properties are reported for the sum of items, without imputation, at baseline.

| Domain | Items | Baseline Properties | | | | |
|---|---|---|---|---|---|---|
| | | Missing | Min | Max | Skew | Kurt |
| Beliefs about risk | | 23 | 5 | 15 | -0.47 | -0.07 |
| | People with a healthy lifestyle have a lower risk of dementia | | | | | |
| | There is nothing we can do to prevent dementia (R) | | | | | |
| | People with an active mind do not develop dementia (R) | | | | | |
| | Dementia is inevitable in older age (R) | | | | | |
| Beliefs about treatment | | 14 | 6 | 15 | 1.87 | 6.81 |
| | There is value in a person with dementia being given a formal diagnosis from a doctor | | | | | |
| | It is likely that a person with dementia's situation will improve with social support | | | | | |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
|  | We can do a lot now to improve the lives of people with dementia |  |  |  |  |  |  |
|  | It is better for people living with dementia to be forced into treatment by their doctor even if they do not want to (R) |  |  |  |  |  |  |
| Beliefs of living with dementia |  | 18 |  | 17 | 32 | -0.47 | -0.88 |
|  | People with dementia can enjoy life |  |  |  |  |  |  |
|  | A person living with dementia is impulsive and unpredictable (R) |  |  |  |  |  |  |
|  | People with dementia are dangerous more often than not (R) |  |  |  |  |  |  |
|  | People living with dementia are a good source of knowledge |  |  |  |  |  |  |
|  | People living with dementia can pass on valued traditions/cultural beliefs |  |  |  |  |  |  |
|  | People living with dementia can participate in a variety of activities |  |  |  |  |  |  |
|  | People living with dementia can be |  |  |  |  |  |  |

|  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|
|  | supported to make reasonable decisions |  |  |  |  |  |
|  | It is difficult to communicate with people living with dementia (R) |  |  |  |  |  |
|  | People living with dementia would be incapable of feeling other people’s worries or concerns (R) |  |  |  |  |  |
| Care beliefs |  | 18 | 9 | 19 | -0.61 | -0.26 |
|  | It is better for the family, if people living with dementia enter a nursing or residential care home (R) |  |  |  |  |  |
|  | A nursing or residential care home is the best place for people with dementia (R) |  |  |  |  |  |
|  | If I had a family member with dementia it would be best to move them to a nursing home or residential care even if they didn’t want to go (R) |  |  |  |  |  |
|  | People with dementia pose a risk to their neighbours unless they are in a hospital or nursing home.  (R) |  |  |  |  |  |
|  | It is important to remove family responsibilities |  |  |  |  |  |

| | | | | | | |
|---|---|---|---|---|---|---|
| | from people living with dementia so as not to stress them (R) | | | | | |
| Secrecy | | 17 | 8 | 26 | 0.44 | -0.48 |
| | If you had a close relative who had dementia, you would advise him or her <u>not</u> to tell anyone about it. | | | | | |
| | If you were in treatment for dementia you would worry about certain people finding out about your treatment. | | | | | |
| | If you had treatment for dementia the best thing would be to keep it a secret. | | | | | |
| | People should not hide the fact they have dementia. | | | | | |
| | In view of society's negative attitudes towards people living with dementia, you would advise people with dementia to keep it a secret. | | | | | |
| | If I had dementia, I would encourage my family to keep it a secret. | | | | | |

| |
|---|
| If I had dementia, I would make an effort to keep my dementia a secret when meeting people |
| If I had dementia and was receiving treatment for another condition, I would keep my dementia a secret from the doctor |

**Appendix. C**

***Supplementary table 2:*** Beliefs towards dementia pre- and post- the anti-stigma intervention amongst general public. Inclusive of imputation of mear missing data.

| | | Pre | Post | Intervention | |
|---|---|---|---|---|---|
| | n | Mean (SD) | Mean (SD) | *Partial eta sq* | p |
| Risk beliefs (↑ negative beliefs) | 53 | 10.22 (2.37) | 9.42 (2.63) | 0.07 | 0.06 |
| Treatment beliefs (↑ negative beliefs) | 54 | 8.15 (1.62) | 6.60 (2.05) | 0.26 | <0.001 |
| Living with dementia beliefs (↑negative beliefs) | 54 | 25.53 (4.09) | 22.11 (3.83) | 0.35 | <0.001 |
| Care beliefs (↑negative beliefs) | 52 | 15.12 (2.74) | 12.49 (3.12) | 0.33 | <0.001 |
| Secrecy (↑ more secrecy) | 55 | 16.07 (4.93) | 14.64 (4.54) | 0.07 | 0.05 |

**Appendix D**

***Supplementary table 3:*** Pre-test knowledge about the cause of dementia amongst the general public

| | Not at all likely | Not Likely | Somewhat Likely | Very Likely | Don't know | Missing |
|---|---|---|---|---|---|---|
| Brain Disease | 1 (1.7%) | 0 (0.0%) | 7 (11.9%) | 48 (81.4%) | 2 (3.4%) | 1 (1.7%) |
| Unhealthy Lifestyle | 11 (18.7%) | 7 (11.9%) | 17 (28.9%) | 19 (32.3%) | 4 (6.8%) | 1 (1.7%) |
| Gods Will | 22 (37.4%) | 9 (15.3%) | 10 (17.0%) | 11 (18.7%) | 6 (10.2%) | 1 (1.7%) |
| Bad Luck | 19 (32.3%) | 11 (18.7%) | 7 (11.9%) | 6 (10.2%) | 15 (25.5%) | 1 (1.7%) |
| Normal Aging | 4 (6.8%) | 2 (3.4%) | 21 (35.7%) | 28 (47.6%) | 2 (3.4%) | 2 (3.4%) |
| Brain Injury | 9 (15.3%) | 2 (3.4%) | 11 (18.7%) | 33 (56.1%) | 3 (5.1%) | 1 (1.7%) |
| Lack of family support | 17 (28.9%) | 7 (11.9%) | 19 (32.3%) | 11 (18.7%) | 3 (5.1%) | 2 (3.4%) |
| Witchcraft | 30 (51.0%) | 7 (11.9%) | 2 (3.4%) | 5 (8.5%) | 13 (22.1%) | 2 (3.4%) |

***Supplementary table 4:*** Post-test knowledge about the cause of dementia amongst the general public

| | Not at all likely | Not Likely | Somewhat Likely | Very Likely | Don't know | Missing |
|---|---|---|---|---|---|---|
| Brain Disease | 2 (3.4%) | 2 (3.4%) | 9 (15.25) | 42 (71.2%) | 0 (0.0%) | 4 (6.8%) |
| Unhealthy Lifestyle | 10 (16.9%) | 1 (1.7%) | 20 (33.9) | 23 (39.0%) | 1 (1.7%) | 4 (6.8%) |
| Gods Will | 16 (27.1%) | 9 (15.3%) | 12 (20.3%) | 16 (27.1%) | 1 (1.7%) | 4 (6.8%) |
| Bad Luck | 24 (40.7%) | 8 (13.6%) | 9 (15.3%) | 10 (16.9%) | 4 (6.8%) | 4 (6.8%) |
| Normal Aging | 6 (10.2%) | 8 (13.6%) | 14 (23.7%) | 27 (45.8%) | 0 (0.0%) | 4 (6.8%) |
| Brain Injury | 7 (11.9%) | 6 (10.2%) | 13 (22.0%) | 27 (45.8%) | 1 (1.7%) | 5 (8.5%) |
| Lack of family support | 5 (8.5%) | 5 (8.5%) | 16 (27.1%) | 27 (45.8%) | 1 (1.7%) | 5 (8.5%) |
| Witchcraft | 34 (57.6%) | 6 (10.2%) | 8 (13.6) | 1 (1.7%) | 4 (6.8%) | 6 (10.2%) |

***Supplementary table 5:*** Pre-test knowledge about the cause of dementia amongst the CHWs

| | Not at all likely | Not Likely | Somewhat Likely | Very Likely | Don't know | Missing |
|---|---|---|---|---|---|---|
| Brain Disease | 1 (10.0%) | 0 (0.0%) | 1 (10.0%) | 8 (80.0%) | 0 (0.0%) | 0 (0.0%) |
| Unhealthy Lifestyle | 1 (10.0%) | 2 (20.0%) | 5 (50.0%) | 1 (10.0%) | 1 (10.0%) | 0 (0.0%) |
| Gods Will | 3 (30.0%) | 2 (20.0%) | 1 (10.0%) | 2 (20.0%) | 2 (20.0%) | 0 (0.0%) |
| Bad Luck | 4 (40.0%) | 3 (30.0%) | 1 (10.0%) | 1 (10.0%) | 1 (10.0%) | 0 (0.0%) |
| Normal Aging | 3 (30.0%) | 1 (10.0%) | 2 (20.0%) | 4 (40.0%) | 0 (0.0%) | 0 (0.0%) |
| Brain Injury | 0 (0.0%) | 2 (20.0%) | 4 (40.0%) | 3 (30.0%) | 1 (10.0%) | 0 (0.0%) |
| Lack of family support | 1 (10.0%) | 1 (10.0%) | 5 (50.0%) | 2 (20.0%) | 1 (10.0%) | 0 (0.0%) |
| Witchcraft | 6 (60.0%) | 0 (0.0%) | 1 (10.0%) | 1 (10.0%) | 2 (20.0%) | 0 (0.0%) |

***Supplementary table 6:*** Post-test knowledge about the cause of dementia amongst the CHWs

| | Not at all likely | Not Likely | Somewhat Likely | Very Likely | Don’t know | Missing |
|---|---|---|---|---|---|---|
| Brain Disease | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) | 10 (100.0%) | 0 (0.0%) | 0 (0.0%) |
| Unhealthy Lifestyle | 2 (20.0%) | 1 (10.0%) | 3 (30.0%) | 4 (40.0%) | 0 (0.0%) | 0 (0.0%) |
| Gods Will | 3 (30.0%) | 4 (40.0%) | 2 (20.0%) | 1 (10.0%) | 0 (0.0%) | 0 (0.0%) |
| Bad Luck | 7 (70.0%) | 2 (20.0%) | 1 (10.0%) | 0 (0.0%) | 0 (0.0%) | 0 (0.0%) |
| Normal Aging | 0 (0.0%) | 1 (10.0%) | 5 (50.0%) | 4 (40.0%) | 0 (0.0%) | 0 (0.0%) |
| Brain Injury | 0 (0.0%) | 0 (0.0%) | 2 (20.0%) | 8 (80.0%) | 0 (0.0%) | 0 (0.0%) |
| Lack of family support | 1 (10.0%) | 1 (10.0%) | 5 (50.0%) | 3 (30.0%) | 0 (0.0%) | 0 (0.0%) |
| Witchcraft | 8 (80.0%) | 1 (10.0%) | 0 (0.0%) | 1 (10.0%) | 0 (0.0%) | 0 (0.0%) |

***Supplementary table 7:*** Attitudes and beliefs towards dementia pre- and post- the programme amongst Community Health Workers. Inclusive of imputation of mean where < 50% missing data.

| | Imputation | | | | |
|---|---|---|---|---|---|
| | | Pre | Post | | |
| | n | Mean (SD) | Mean (SD) | *Partial eta sq* | p |
| Risk beliefs (↑ negative beliefs) | 10 | 9.80 (2.35) | 8.60 (2.36) | 0.19 | 0.18 |
| Treatment beliefs (↑ negative beliefs) | 10 | 7.23 (1.20) | 5.50 (0.85) | 0.60 | 0.01 |
| Living with dementia beliefs (↑negative beliefs) | 9 | 23.85 (2.98) | 23.11 (4.62) | 0.04 | 0.57 |
| Care beliefs (↑negative beliefs) | 10 | 13.13 (2.94) | 12.10 (3.38) | 0.08 | 0.40 |
| Secrecy (↑ more secrecy) | 10 | 14.04 (1.94) | 12.90 (4.15) | 0.08 | 0.40 |