

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.

References

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- [2] Stangl AL, Earnshaw VA, Logie CH, Van Brakel W, C. Simbayi L, Barré I, Dovidio JF (2019) The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Med* **17**, 1–13.
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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	<p>People with a healthy lifestyle have a lower risk of dementia</p> <p>There is nothing we can do to prevent dementia (R)</p> <p>People with an active mind do not develop dementia (R)</p> <p>Dementia is inevitable in older age (R)</p>	23	5	15	-0.47	-0.07
Beliefs about treatment	<p>There is value in a person with dementia being given a formal diagnosis from a doctor</p> <p>It is likely that a person with dementia's situation will improve with social support</p>	14	6	15	1.87	6.81

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 not 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 missing data.

		Pre	Post	Intervention	
	n	Mean (SD)	Mean (SD)	<i>Partial eta sq</i>	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.

	n	Imputation		<i>Partial eta sq</i>	p
		Pre Mean (SD)	Post Mean (SD)		
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

