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Alzheimer's & Dementia
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MINISTRY OF HEALTH

GOVERNMENT OF
MAKUENI
COUNTY



ADDRESSING DEMENTIA STIGMA IN KENYA

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Background

- There is limited knowledge, perceived negative stereotype, prejudice, and discrimination of the public toward people with dementia and their family carers [1].
- Perceptions including attributions of dementia to witchcraft, combined with constrained healthcare systems lead to stigma manifested in the form of patchy diagnostic pathways, neglect and abuse [2].
- Stigma affects quality of life of people with dementia and their families yet interventions to reduce it are limited in developing countries [3].

[1] Nguyen, T. and Li, X., 2020. Understanding public-stigma and self-stigma in the context of dementia: a systematic review of the global literature. *Dementia*, 19(2), pp.148-181.

[2] Musyimi, C.W., Ndetei, D.M., Evans-Lacko, S., Oliveira, D., Mutunga, E. and Farina, N., 2021. Perceptions and experiences of dementia and its care in rural Kenya. *Dementia*, 20(8), pp.2802-2819.

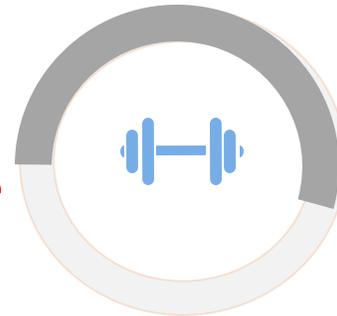
[3] Herrmann, L.K., Welter, E., Leverenz, J., Lerner, A.J., Udelson, N., Kanetsky, C. and Sajatovic, M., 2018. A systematic review of dementia-related stigma research: can we move the stigma dial?. *The American Journal of Geriatric Psychiatry*, 26(3), pp.316-331.

Beliefs and attitudes towards people with dementia-Kenya n=59



82%

Dementia is **caused in part due to; normal ageing.**



62%

Nothing can be done to prevent dementia/don't know if dementia is preventable.



65%

People with dementia should be **worried about discrimination by doctors** unwilling to provide treatment



90%

People with dementia **do not understand simple instructions.**

The gap

Anti-stigma interventions in low-income and middle-income countries: a systematic review

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Summary

Background Stigma exacerbates power imbalances and societal disparities, significantly impacting diverse identities and health conditions, particularly for low and middle-income countries (LMICs). Though crucial for dismantling harmful stereotypes, and enhancing healthcare utilisation, existing research on anti-stigma interventions is limited with its condition-focused approach. We aimed to thoroughly evaluate peer-reviewed and non-peer-reviewed literature for a comprehensive review of anti-stigma interventions for diverse identities and all health conditions in LMICs.



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RESEARCH ARTICLE

Scope of anti-stigma programs against Alzheimer's disease: A scoping review

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Abstract

This study identifies and reports evidence related to key guidelines for intervention programs aimed at reducing social stigma associated with Alzheimer's Disease. This scoping review followed the methodology of the Joanna Briggs Institute. The databases searched included: SCOPUS, PubMed, Science Direct, Taylor and Francis, Google Scholar, JBI, Prospero, and Cochrane Library. The STROBE statement was used to organize and draft the protocol. Of the 2275 initial studies, 22 articles were identified for the analysis of emerging categories: social stigma assessment, measurement, and intervention strategies. Of the 2275 initial studies, 22 articles

Dementia anti-stigma intervention (DASI)

ANTI-STIGMA INTERVENTION

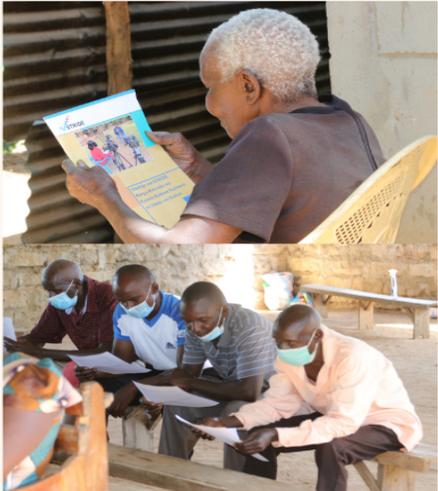
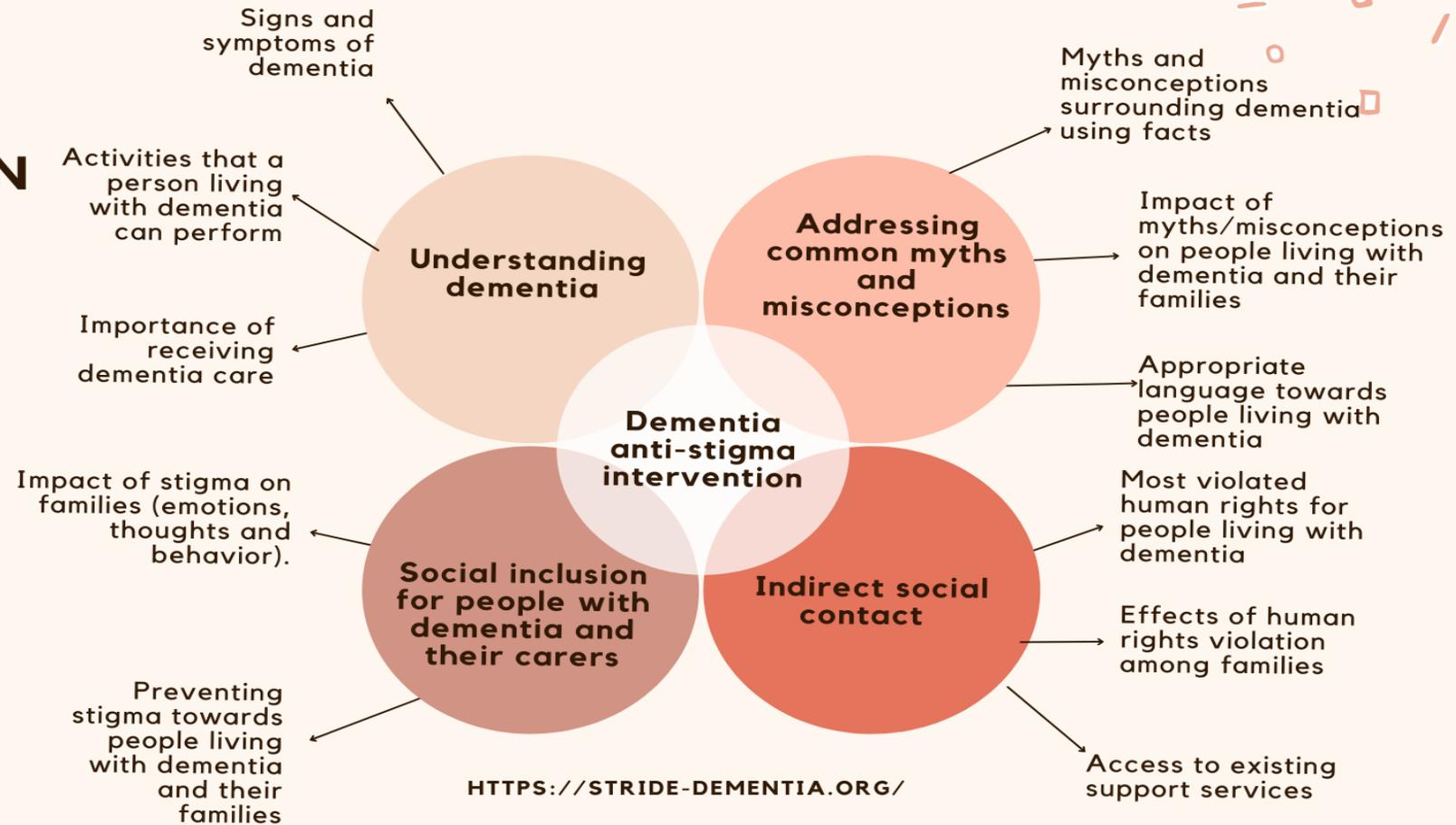


Photo: Courtesy of STRiDE Kenya



Methods used

- Trainer – Ten Community Health Promoters (CHPs) in Makueni County, Kenya participated in a 5-day training on how to implement the dementia anti-stigma intervention (DASI) and use appropriate facilitator skills within the manual.
- Four psycho-educational group sessions (1.5 to 2 hours) were delivered by five pairs of CHWs to 59 members of the general public - aimed at creating awareness among members of the general public.
- Stigma-related outcome conducted at **baseline and one-month post the intervention**

Acceptability and Feasibility of a Community Dementia Stigma Reduction Program in Kenya

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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, with each workshop lasting 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.

Conclusions: The intervention was accessible and feasible in rural Kenya, while 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.

Keywords: Alzheimer's disease, anti-stigma, dementia, feasibility, general public, intervention

INTRODUCTION

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 infor-

mation, 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

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Attitudes To Dementia World Alzheimer Report 2024 Survey



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).

”

Inclusivity: In most cases, 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."

Male caregiver of a person with dementia

”

Knowledge: “[*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.”

Female member of the general public

Next steps



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- In order to ascertain whether some beliefs that are deeply ingrained in the communities can improve in the long-term, we are testing the effectiveness of the DASi in Kenya with funding from the **Alzheimer's Association**.
- Evaluation will be performed by reporting the change in dementia-related knowledge, attitudes behavior changes at **6-and 12 months after the intervention**.
- Given the expected increase in the number of people with dementia by 2050, approaches that raise awareness could provide a route to improve the lives of 100,000s of people with dementia in Kenya by tackling stigma



Key lessons learnt

- Involving people with dementia, their carers and key stakeholders in developing and implementing anti-stigma interventions by allowing them to express their views is crucial to ensure that the interventions are specific to its target users.
- Addressing dementia-related stigma through education and support can improve help-seeking behaviour and contribute to integrating dementia screening and improving its uptake by local communities.
- Use of task-sharing approaches to create awareness provides sustainability opportunities - *"I liked our trainers. These are people well known to us."*

Male Member of the general public

