Dementia Anti-Stigma Intervention

Facilitator’s manual: Train-the-Trainer Program

Introduction

This manual was developed within the Strengthening Responses to Dementia in Developing Countries (STRiDE) project using the Medical Research Council (MRC) framework for the development and evaluation of complex interventions. STRiDE was implemented in seven countries (Brazil, India, Indonesia, Jamaica, Kenya, Mexico and South Africa) between 2018 and 2022 and aimed at building local capacity to support the development, implementation and evaluation of national strategies to deliver appropriate, equitable, effective and affordable dementia care. One of the objectives of STRiDE Kenya team led by Professor David Ndetei, Dr. Christine Musyimi, Mrs Elizabeth Mutunga and Mr Levi Muyela was to reduce stigma by increasing understanding and awareness of dementia among healthcare providers and community members. A situational analysis to better understand baseline perceptions among: members of the general public, healthcare providers (clinicians and community health workers) and carers of people living with dementia was then conducted to respond to this need. This resulted in a dementia anti-stigma intervention that was tested in a rural setting in Kenya. The manual can also be used in similar low resource settings.

The main contributors of the manual are:

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8. Health care providers, carers of people living with dementia, members of the general public in Makueni County, Kenya.

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Contents:

Type of program:

This is a train-the-trainer program comprising:

a) Trainer (Community Health Volunteers (CHVs)) training/. educational event (5-day training) on how to implement an anti-stigma intervention,

b) Four psycho-educational group sessions delivered by CHVs aimed at creating awareness among members of the general public and

c) a video-based social contact element (included in the four sessions) of individual experiences of living with and caring for persons living with dementia.

Training of CHVs to deliver the intervention:

This involves a 5-day face to face training. Each day is dedicated to a specific topic, with one day dedicated to logistical skills of managing and facilitating future sessions. Extensive role plays are conducted after each session.

Intervention delivery to members of the general public:

This involves a 4-day face to face intervention delivered to members of the general public on a weekly/bi-weekly basis. Each session is dedicated to specific topics and is estimated to take between 60-90 minutes.

Expected Outcomes:

Stigma-related dementia knowledge, dementia-related attitudes and intended behaviour.

Session completion expectation:

CHVs should ensure that the main activities for the session or the learning goals are achieved. Participants (CHVs and the general public) are also expected to participate in all sessions in an interactive manner. However, for unavoidable circumstance/emergencies, we have included a recap activity at the beginning of every session to capture specific aspects of the previous session, particularly the learning goals.

Learning objectives:

In every session, there are key messages that need to be covered for each session to ensure CHVS are within these parameters even when participants deviate through story telling. CHVs should introduce each session with greetings, recap (sessions 2-4) and the learning objectives.

Anticipated limitations:

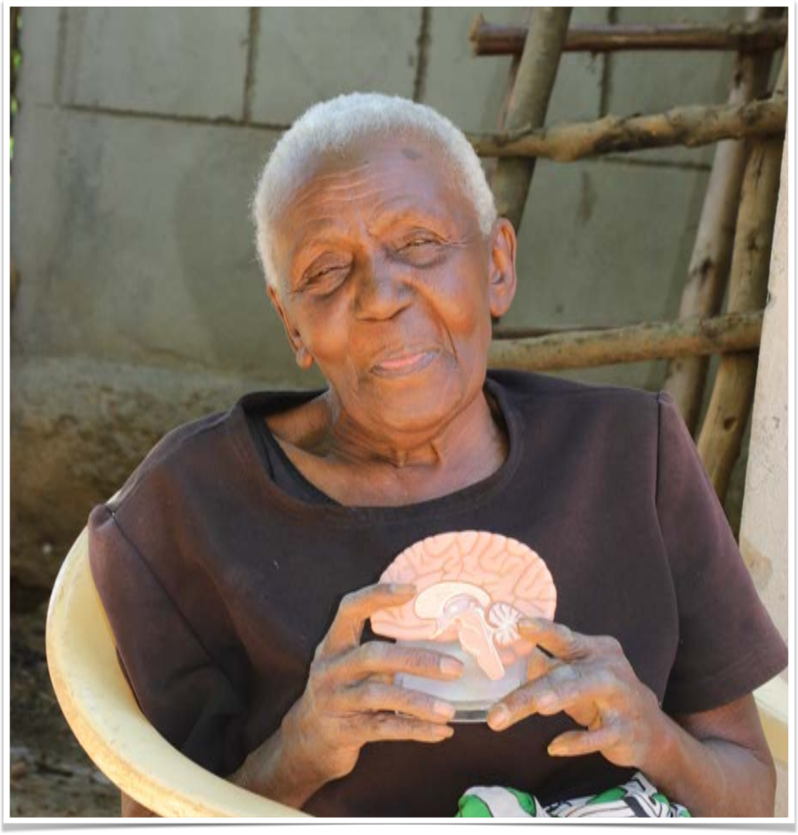
We have taken note of the possibilities of CHVs not being able to address a challenge through positive feedback but rather acting surprised or shouting when faced with an idiosyncratic or strange response. At the end of this manual, we have added some skills for CHVs. For instance, we emphasize the importance of using a friendly tone and positive language and avoiding statements such as “but”, “you should not”, “that is wrong” and discussed on use of statements like “remember to…”, “do not forget to…”, “another idea would be to….”, at the same time acknowledging a positive response with a labeled praise such as “thank you for describing how one would approach these issues”. These are important to reduce stigma – **please see facilitators’ skills.**

We also acknowledge that CHVs would need a simplified guided version due to the levels of education and this may not be applicable in all low resource settings across the world since some CHVs may feel demeaned and may not be responsive to the model. To address this, we have provided a detailed manual that can be used by lay workers in low resource settings. For adaptation in other dissimilar settings or where CHVs have higher literacy levels, researchers/intervention implementers can opt to cut down specific details.

General instructions:

1. Statements in *italics* should NOT be read out to participants.
2. Statements NOT in italics can be summarized or read out to participants.
3. Check on the time allocated for each section so that the time is evenly distributed across all sections.
4. Please ensure to go through the sessions prior to training so as to familiarize yourself with the sessions.
5. Facilitator skills are not for the general public but a guide for the facilitators.

SESSION 1: UNDERSTANDING DEMENTIA



Learning objectives

By the end of this session, participants are expected to;

i. Understand what dementia is and how dementia changes over time.

ii. Recognize the importance of receiving treatment and support.

iii. Know the kind of activities that a person living with dementia can do remembering to focus on the individual and not the disease.

Materials for the session

- *Pen/paper*
- *Manual*

Activity 1: Understanding dementia (20-25 minutes)

Ask participants questions such as: What comes to your mind when you hear the term dementia? How would you know someone has dementia?

Dementia (umbrella term) refers to a group of symptoms caused by other conditions that cause changes in the brain which affect mental abilities such as loss of thinking and memory. The most common type is Alzheimer's disease. Dementia may make it more difficult for people to remember things concentrate or do some things they could do before. Although people living with dementia can continue to participate in all types of activities, they may require more help or support. Over time, these symptoms caused by dementia may slowly increase. This means it is important to identify dementia early on so that the person can get help to slow down this process.

Early signs of dementia vary but the common ones include;

i. Difficulty recalling recent events/forgetfulness.
ii. Behaviour changes such as depression or being easily irritable.
iii. Increased confusion.
iv. Reduced concentration and attention.
v. Reduced or loss of ability to do everyday tasks like dressing, cooking etc.

NB: Forgetfulness caused by dementia involves difficulty in learning new things and/or forgetting previously learned things. It also may consist of losing belongings or getting lost more easily. It is important to rule out other mental health illnesses before stating that someone has dementia.

Advanced symptoms of dementia include:

i. Difficulty swallowing
ii. Pain on movement
iii. Agitation
iv. Lack of emotion and/or motivation
v. Breathing difficulties

Activity 2: Importance of receiving treatment and support (10-15 minutes)

Ask participants to list down on a piece of paper why it is important for people living with dementia to receive care and support and randomly ask participants to read out their responses.

Early identification of dementia has several benefits both for the person living with dementia and the family such as:

i. **Access to care and support:** Early diagnosis allows the person living with dementia to easily access medication and/or support services. Early identification also helps to have an idea of how the disease will progress and therefore determine the type of care needed.

ii. **Adjustment to diagnosis:** Early diagnosis gives people living with dementia time to adjust to the condition, and better make adaptations in life to maintain good mental health.

iii. **Planning for the future:** When an individual is identified to have dementia, fear develops as signs/symptoms may make certain things more difficult. Diagnosis can help people living with dementia and their families to plan for the future. Receiving support helps with reducing this fear which may in turn lead to better planning. Planning includes care planning, legal affairs and financial decisions and even how to cope moving forward.

iv. **Acknowledging/being aware of human rights of people living with dementia:** People have the right to know about their illness. They also have a right to correct medication and proper treatment including not being restrained.

Activity 3: Activities a person living with dementia can do (15-20 minutes)

Engage participants in a discussion and ask each participant to share with their neighbour what activities a person living with dementia can do.
Examples*; watering plants, bringing food to the table, clearing utensils after a meal etc. Each participant should share their neighbour's responses.*

- Most favourable activities for a person living with dementia are those which bring about memories of the person before the disease e.g. looking at their photos or those of their loved ones.

- Activities can be different depending on the age or stage of the condition of the person living with dementia. One can choose activities that are more specific to the person's interest. A good place to start would be to find out the person's hobbies and pick something in line with that while taking into consideration that some activities may require supervision.

- It is important to note however, that one should not pick activities that the person living with dementia may view as childish but also not pick on activities that may be too difficult to do due to the condition. The idea is to find a balance.

- Just because a person living with dementia cannot complete a task successfully, this does not mean that they should be stopped from doing the task as they may still get enjoyment from them. Obviously, it is important to be keen that these activities are not putting anyone's health or safety at risk.

- Remember it is important to focus on the individual and not the disease because before the condition, this was a person who could function without any assistance.

- People living with dementia have feelings and emotions (just like the rest of us) which can be hurt if we do not handle them with care. It is important to put ourselves in such shoes and ask how we would want to be treated if we found ourselves in such a position.

SESSION 2: ADDRESSING COMMON MYTHS AND MISCONCEPTIONS

Recap activity for session 1 - reflection and feedback (10-15 minutes)

1. What is dementia and what signs are common for a person living with dementia
2. What are the activities that a person living with dementia can do? What important things does one need to have in mind while selecting activities for a person living with dementia?
3. What new insights/knowledge do you have from yesterday's discussions (anything to add or improve on)?

Learning objectives

By the end of this session, participants are expected to;

- i. *Define myths/misconceptions.*
- ii. *Know and identify myths and misconceptions surrounding dementia using facts.*
- iii. *Know the effects/impact of myths/misconceptions on people living with dementia and their families.*
- iv. *Know what terms/language to avoid or use while referring to people living with dementia.*

Materials for the session

- ✓ *Pen and Paper*
- ✓ *Manual*

Activity 1: Introduction

Ask participants to raise their hands if they know someone who has dementia. As a starting point, state that there is something we can do to support people living with dementia and improve their life.

- Given the lack of knowledge on dementia, myths and misconceptions have been created. This results in stigma towards people living with dementia and their families leading to feelings of loneliness.
- Myths and misconceptions are defined as false beliefs and opinions about issues.
- By identifying the myths and the counter facts surrounding dementia, awareness is raised and support can be extended to people living with dementia and their families.

Activity 2: Dementia myths/misconceptions (10-15 minutes)

Each member in the group should participate in all activities (there is no wrong or right answer)

- ✓ *Divide the team into two groups.*
- ✓ *Ask each of the groups to choose a note taker, a facilitator and a presenter within themselves.*
- ✓ *Ask the members to get a paper and divide it into two columns.*
- ✓ *Ask the members of each group to come up with myths about dementia and list them on one side of the paper. This should take 5 minutes.*
- ✓ *After group discussions, ask the presenters to share the list of false beliefs identified within their group in a plenary session (NB: more time should be spent discussing the facts as opposed to the myths as sometimes too much focus on the myths can make people remember them as facts later on).*
- ✓ *Add more information (if any) to the presented lists with the myths on the table in the manual at the end of the plenary session.*

Activity 3: Dementia counter facts (10-15 minutes)

- ✓ In the same groups, ask the members to choose another note taker, facilitator and a presenter
- ✓ Ask the members to come up with the counter facts about dementia and list them on the other side of the paper. This should take 5 minutes.
- ✓ After group discussions, ask the presenters to share the facts in front of the members on the other group in the plenary session.
- ✓ Give opinions on the prepared list with facts from the table at the end of the plenary session.

Table 1: Myths and misconceptions and how to react to them with facts (C. Musyimi, Mutunga, & Ndetei, 2019; C. W. Musyimi et al., 2021)

NB: While discussing the content of this table with members of the general public, it is important to mention that the list is not exhaustive and all the myths may not be covered during the session. CHVs could focus on just a few examples to create an understanding on how myths can create stigma and interfere with access to care and support for people living with dementia and their families.

MYTHS/MISCONCEPTIONS	FACTS
1. People living with dementia are cursed, practice witchcraft or have stolen from a home dominated/ protected by a traditional healer.	○ Signs of dementia are often times mistaken and confused for other things that are permissible within the socio-cultural practice of a society (Nwakasi et al., 2019). ○ People do not get dementia as a consequence of their actions, but rather due to complications in the brain which lead to development of symptoms such as memory loss, language and communication impairments, impaired reasoning, judgment and planning etc. (Duong, Patel, & Chang, 2017).

MYTHS/MISCONCEPTIONS	FACTS
2. Dementia affects people who once held senior positions and retired. They were ‘thinking high’ of themselves and assuming other people do not exist. What goes up must come down!	The condition is not the ‘fault’ of the individual (UK, 2007). Even when you look at lifestyle factors across a lifespan (from childhood to old age), 60% of risk factors are unknown (Livingston et al., 2020).
3. Dealing with a person living with dementia is like a source of stress	The well-being of carers can be enhanced through strategies which lead to reduced perception of burden, with respite or alternative services providing tangible relief from burden (McConaghy and Caltabiano, 2005). In addition, treatment modalities that have been helpful are counseling the primary carers, family meetings, and support groups for carers (Zarit and Zarit, 1982).
4. A person living with dementia is a small baby with little brains	Although some of the behaviors that people living with dementia have may be similar to those of children, the causes for the behavior are totally different. (Cayton, 2006). For example, some behaviors like incontinence may occur at middle or later stages (Sakakibara, Uchiyama, Yamanishi, & Kishi, 2008). This is not their fault, it is just a symptom of the illness. A person living with dementia needs more support with some things that they used to do on their own and this can be done while still respecting them.
5. A person living with dementia is a gone case and nothing can be done	Many people living with dementia diagnosis lead active and meaningful lives (Newman, 2020)
6. People living with dementia are really confused and they cannot understand a thing	A person living with dementia can be fully understood (his or her history, likes/dislikes, and so on (UK, 2007). They may be confused sometimes, but this can also change. For example, some people may be more confused at night and so asking them questions at another time of day or when they feel less confused may be helpful.

MYTHS/MISCONCEPTIONS	FACTS
7. People living with dementia need to be restrained at home so that they do not get lost.	● People living with dementia should not be restrained, rather, the outside environment should be made more friendly to accommodate them since their orientation to a particular place, level of social disturbance and level of interest depend on the quality of care provided in that environment (Blackman et al., 2003). ● People living with dementia also have a right to proper medication and proper management and treatment methods including not being restrained.
8. Dementia disease is not madness, but they are close to each other.	● Dementia (umbrella term) refers to a group of symptoms caused by other conditions that affect mental abilities such as loss of thinking and memory. ● Early detection allows the person living with dementia to easily access medication or support services. ● However, some types of dementia can lead to changes in visual perceptions (Mosimann et al., 2004).
9. People living with dementia are always ordering people around, demanding for things that are not available.	People living with dementia can become aggressive at times due to the frustrations that come with being ill e.g. inability to complete daily tasks or losing memory. It is important to approach them calmly and use simple step by step instructions being careful not to also treat them as a child (Gormley, Lyons, & Howard, 2001)
10. Nobody cares about people living with dementia	Despite the government not having structures that specifically support people living with dementia, there are non-governmental organizations in Kenya that offer support to people living with dementia through helplines, support groups or training for carers. We acknowledge that most of these organizations touch a small population and are based in urban populations (Comas-Herrera et al., 2020).
11. Dementia is not preventable.	Recent research suggests that with proper diet, regular exercise, continuous cognitive (mind/psychological) stimulation and reduced intake of alcohol may help to reduce chances of developing dementia (Cedars-Sinai, 2020)

MYTHS/MISCONCEPTIONS	FACTS
12. People living with dementia are prone to violence.	Not all people living with dementia become aggressive but some may express frustration through actions after diagnosis. Some guidelines to avoid provoking them to aggression include (The Recovery Village, 2021); i. Do not ask more than one question at a time ii. Avoid loud noises iii. Avoid physically uncomfortable situations
13. Dementia is not fatal.	Some progressive forms can be fatal especially in people aged 65 years or older (The Recovery Village, 2021). Depending on the age of the person, average life expectancy following is 6.7 years (Wolters et al., 2019).
14. People living with dementia are 'sufferers'/ 'demented'/ 'victims' because they have been 'thinking high.'	Dementia is not the 'fault' of the individual (UK, 2007). Referring to people living with dementia as people living with dementia prevents stigma that comes from labeling. It is important to separate the individual form the condition. Language matters.
15. Dementia is a disease for old people	Dementia is more prevalent in older population (>65 years) but can also exist within a younger population (below 65 years) as early onset dementia (EOD)(Werner, Stein-Shvachman, & Korczyn, 2009)

Activity 4: Using appropriate language (5 mins)

- It is important to note that the language we use to refer to people living with dementia needs to be respectful since they are individuals with emotions just like the rest of us. There are offensive words that devalue the person living with dementia in a way to show that a life with dementia is not worth living or that people living with dementia cannot be helpful.
- Some terms we use can be hurtful to both the carer and the person living with dementia. What are the hurtful terms used before and how can we change them?
- Consider using terms such as 'person living with dementia' instead of '*chizi*' or 'dementia patient'. Alternatively, you can ask the individual the term he or she prefers to identify themselves with.
- Empathy is described as the ability to share and understand the feelings of another or putting oneself into another's shoes. In this case, how might the person living with dementia and/or the carer feel when negative terms are used?

At the end of the activities, engage in a question and answer discussion. Respond to any additional questions and summarize the session (10 minutes)

SESSION 3: INDIRECT CONTACT (VIDEO-BASED) TO AMPLIFY VOICES OF PERSONS WITH DEMENTIA AND THEIR CARERS

Recap activity for session 2 - reflection and feedback (10-15 minutes)

Instructions

- ✓ Participants can work alone or in pairs.
- ✓ *Ask participants to get a piece of paper*
- ✓ *Tell them to answer the following questions on the piece of paper;*
    1. *What did they learn in the previous session?*
    2. *What did they understand by myths/misconceptions (allow participants to identify a myth and a counter myth)*
    3. *Why is it important to understand myths/misconceptions?*
    4. *What is still unclear from the previous session?*
    5. *What new insights/knowledge do they have from yesterday's work (anything to add or improve on)?*

Ask them to present their points (everyone should participate). Allow participants to clarify any questions for each other. The facilitator can add where need be.

Learning objectives

The goal of this session is to know;

- i. *Human rights and to whom they apply*
- ii. *Human rights for people living with dementia that are mostly violated.*
- iii. *How being more open could be more helpful and gives one access to help*
- iv. *How carers are affected and how they can be supported*
- v. *Where carers can access support services.*

Materials for the session

- *Internet/downloaded video*
- *Smartphone /laptop*
- *Pen/paper.*

✱ ***The facilitator (CHV) can share the video prior to the session or can watch the video in groups during the session using the CHV's phone.***

Activity 1: What are human rights? Open discussion (10 minutes)

These are the basic rights and freedoms that a human is entitled to from birth till death regardless of race, sex, nationality, ethnicity, language, religion, or any other status.

Examples of human rights in relation to people living with dementia:

- ✓ One has a right to know their diagnosis if they want, and a right not to know if they do not want to know.
- ✓ They should be explained to in a language that they can understand e.g. explaining dementia preferably using symptoms/signs if there is no non-stigmatizing word for dementia in the local language.
- ✓ Consent (permission from the person diagnosed with dementia) should be sought before involving any family or friends
- ✓ Sensitively discussing how one would like to proceed in future in case they are not able to make decisions due to cognitive decline concerning matters of who will be the main carer, would they want to go to a care home? Or who will be in charge of their properties (if any)?

Activity 2: Social contact (20 minutes)

i. *Introduce the session by;*

- ○ *Explaining to the participants what the video is about.*
- ○ *Asking the members to try and understand the experiences the individuals in the video face.*
- ○ *Asking the members to keep an open mind and think about how seeing the video might challenge their view.*

ii. *Project the video for participants using a laptop or use your phone as the provider to show the video to the group*

iii. *Request for feedback on reflections regarding previous expectations of how they thought a person living with dementia is and copes with life and how do those expectations compare with what was seen in the video*

iii. *Ask participants to highlight the human rights that they think have been violated and what can be done to support people living with dementia, highlighting on the examples provided in the video and indicate what they have learnt from the video in general.*

iv. *What are the issues/concerns raised in the video and how can they be addressed/resolved?*

Notes in response to the video:

- ✓ **Right to non-discrimination -** are people living with dementia or their carers being denied social participation on grounds of having dementia or safety issues?
- ✓ **Right to be free from inhuman and degrading treatment -** are people living with dementia being abused and/or being mistreated e.g. being denied food, being locked up in chains so as to not get lost? Are they made to wait longer in queues compared to other clients in the hospital?
- ✓ **Right to private life, family life and home -** are people living with dementia involved in making decisions concerning their care including issues of their safety or consent to being assessed or who they feel comfortable being their carer?
- ✓ **Right to liberty/freedom -** are people living with dementia free to leave a place even if their safety is under control?
- ✓ **Right to proper medication** - are people living with dementia able to access the medication they need?

How stigma related to violation of human rights affects emotions and behaviour

- ✓ Stigma involves the negative attitudes and discriminating words or actions directed to someone with a particular characteristic such as mental health issues.
- ✓ People living with dementia are highly likely to face stigma from the community and even their family. This greatly affects their emotions, thoughts and behaviour. Stigma leads to fear and anxiety about their health and outcome/end result, feelings of anger and hopelessness about the future. It's likely the individual will

experience grief because of thoughts concerning dying. The individual may also experience low self-esteem because participation in conversations or activities is limited and this may be accompanied with feelings of shame and guilt.

- ✓ The low emotions may lead to negative cognitions and beliefs about one self, the world and the future. These negative thoughts may lead to poor ways of coping like avoidance and isolation. Avoidance may mean that the person living with dementia denies being unwell, and may not seek help. Consequently, this delays diagnosis and treatment thus risking disability. Lack of confidence resulting from stigma may lead to further social isolation as a means to avoid uncomfortable situations.
- ✓ Social discrimination due to stigma from other people may lead to rejection or forced isolation by the family or community. Locking the person away may prevent them from accessing opportunities and their rights as people living with dementia.

Activity 3: Where would a person living with dementia seek help (open discussion)? (5 minutes)

- ✓ Nearest health facility.
- ✓ Friends, neighbours
- ✓ Religious / community support groups.
- ✓ Local organizations.
- ✓ If a person living with dementia is lost, take them to the local administration / area chief.
- ✓ Link them with a social worker to help with locating their families.

Activity 4: Advantages of seeking help (open discussion)? Part of session 2 reflections (10 minutes)

- ✓ Facilitates early diagnosis and also gives the family time to discuss and make decisions on adjustments to make.
- ✓ Helps in planning for dementia care and support whether it’s getting a home carer or going to a care home.
- ✓ It’s an opportunity to get advice from friends, and the community.

- ✓ Reduces the number of advanced cases of people living with dementia.
- ✓ Helps people living with dementia to bond with their families hence reducing the burden of care.
- ✓ Improves outcome of illness.
- ✓ Caregivers and community members will have more knowledge on causes and prevention of dementia.

SESSION 4: SOCIAL INCLUSION FOR PEOPLE WITH DEMENTIA AND THEIR CARERS (CASE VIGNETTE) CARERS

Recap activity for social contact session (10-15 minutes)

Ask members to;

i. *List five rights of persons living with dementia.*

ii. *List support services available for persons with dementia and their carers.*

iii. *Suggest other possible community resources that can be availed to people living with dementia and their carers.*

Learning objectives

i. *To define stigma and provide brief examples of stigma experiences for people living with dementia and their carers*

ii. *To find out how the families react to issues around dementia*

iii. *To know the impact when families respond positively or negatively to issues of dementia.*

iv. *To know how stigma affects persons with dementia and their families (emotions, thoughts and behaviour).*

v. *To know ways of preventing stigma towards these families and supporting families experiencing stigma.*

Materials for the session

- *Pen / paper.*
- *Manuals.*

Activity 1: Case vignette discussion (45 minutes)

i. *Ask participants to read the case vignette (Mr. Kilonzo)*

Case Vignette (imagined story)

Mr. Kilonzo is 70 years old and lives by himself in Makueni County in Kenya since his wife passed away last year. His children have moved to the bigger city to work and can only visit once a month. Over the last few months Mr. Kilonzo has found it more difficult to look after the house and himself. His son noticed that his father does not seem himself and is worried about him and what people may think if they see his father.

a) How do community members treat households they think have dementia? Identify the possible occurrences of stigma from the case vignette.

What is stigma? – "Stigma refers to problems of knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination)" (Evans-Lacko, Henderson, & Thornicroft, 2013; Thornicroft, Rose, & Kassam, 2007). It involves the negative attitudes that lead to hurtful behavior against persons with a particular trait or characteristic. It results to people feeling isolated and alone. Worse still, stigma makes people scared to open up about the challenges they may be facing thus they may not seek help.

Examples of stigma experiences

The aim of this section is to get members of the general public to develop empathy, to reflect on their own behaviour and to think about how they can support and be more inclusive of people living with dementia and their carers in the community.

i. Stigma can appear in many forms for example extension of stigma to an individual close to the person living with dementia. In this case, it may be the neighbour to Mr. Kilonzo or one of his children who visits on monthly basis that experiences the stigma. Those that perpetrate stigma may shout or even be harsh at the individual for what the person living with dementia may have done.

ii. Negative stereotypes can affect how health care workers deliver service to person living with mental issues such as dementia. Mr. Kilonzo is likely to experience this type of stigma in the sense that he may not be diagnosed or may just be told it's a normal part of aging and that people living with dementia never get well thus the family should just take him back home and care for him. The health care workers may even tell the family to prepare to care for him as a child because he's expected to behave like a baby as the disease progresses.

iii. Individuals with dementia can internalize stereotypic (generalized assumptions) negative attitudes held by the public. Based on how Mr. Kilonzo has heard people talk of dementia being the ‘most dangerous disease in the community’, he may internalize this and have self-pity thus leading him to some level of self-stigma .

iv. Negative attitudes can influence people to discriminate against people with mental health issues including dementia. Mr. Kilonzo may experience this from the neighbours and the friends who may want to keep off from him because they may think he has become a ‘fool’ and is no longer of use to them. They may even refer to him as ‘*chizi/mwendawazimu*’.

v. Stigma can also be displayed as a belief that in general, other people have negative attitudes towards people with mental illness (dementia). Mr. Kilonzo and family, after knowing that he has dementia, may think that they are being stigmatized even when people are genuinely concerned with the wellbeing of their father. For example, if they ask how Mr. Kilonzo is doing, the family may think that the community members are mocking Mr. Kilonzo’s condition.

vi. Finally, stigma can be seen through negative attitudes and perceptions reflected through policies, rules in organizations making people with mental health issues such as dementia less deserving of opportunities and care. More often than not, dementia has not been considered a condition to warrant medical attention. Consequently, persons living with dementia may not access benefits associated with other medical conditions like subsidized healthcare costs. Here, Mr. Kilonzo may not afford his healthcare costs because of absence of a government system that solidly offers financial support to people living with dementia.

b) How do you think the family will approach these issues? *(discuss issues of shame, embarrassment, guilt (supernatural causes), loss of hope, anxiety, fear of death)*

After Mr. Kilonzo discovered he’s finding it difficult to look after his house, he may feel ashamed and may avoid revealing symptoms and talking about the difficulties he may be experiencing and may resist asking for help. The family may prevent Mr. Kilonzo from getting outside the house because they don’t want the community to pity them or their father. This may be accompanied by anxiety about Mr. Kilonzo’s prognosis and fear that his health status may worsen and be fatal. It’s also possible the family may lose hope in Mr. Kilonzo getting better because even the health care professionals may not be helping much as far as treating Mr. Kilonzo is concerned. While all may seem lost, the family may be hopeful that faith healers might be the solution to the issue if they think that Mr. Kilonzo’s dementia is a curse and pardon can be achieved if spirituality (faith healers) is brought into the picture.

c) What do you think will be the consequences if the family responded in the following ways:

i. Family members blaming each other *(prevent people from seeking care, discouragements from adopting treatment options, hiding the illness because of perceived stigma and self-blame)*

- Blaming each other would result in arguments and tension within the family and this may negatively affect how the family deals with subsequent family issues.
- Blaming one another may result in the family getting stuck and therefore may prevent the family from seeking care because there would be division and disagreement among the family members.
- It may also create guilt and shame that may lead to the family hiding the illness because they think people would judge and blame them for Mr. Kilonzo's condition.
- In case Mr. Kilonzo finds out that his family is blaming each other, he may avoid their presence and self-isolate because he feels he's the cause of the arguments. This may lead him to self-stigmatize as well.

ii. Family members coming together and seeking more information on dementia presentation, causes and available treatment options?

- As the family works to seek more information on dementia, they'll be open to seeking care and available treatment options for Mr. Kilonzo thereby creating an early opportunity for treatment.
- Togetherness may make the family emotionally stronger in the coping with stigma associated with dementia and this poses a better health outcome for Mr. Kilonzo because then the family can fully support him and be there for him.
- Coming together would improve communication and appreciation for each other's efforts in making Mr. Kilonzo live a quality life.
- As a form of care and support, the family may try to create more time to spend with their father.

d) What can be done to prevent stigma towards these families?

__Hint 1:__ use information learned in session 1-3; e.g. promote the importance of prevention, early screening and treatment. __Hint 2:__ Supportive home-based care: Provide skills on how to support people living with dementia and carers in a home setting e.g. when a person living with dementia gets lost, the community members would redirect the person to their home or call the carer.

i. *Teach the community and the family the language to use while referring to the people living with dementia. For example; instead of 'sick' or 'dementia victim' or 'demented' one should say a person living with dementia or person with dementia.*

ii. *Educate the community on dementia causes and risk factors to avoid people referring to the persons living with dementia as 'cursed' or 'bewitched'.*

iii. *Create awareness outreaches and programs that will influence people to recognize and assess their negative perceptions towards dementia.*

iv. *Encourage support towards the people living with dementia and their families. This can be done by redirecting a lost person with dementia back home or contacting the family.*

v. *On a wider scale, social media can be used to share posts about dementia and how people can support persons living with dementia.*

vi. *Creating social support groups specifically for the carers of persons living with dementia where training sessions can be conducted as well as debriefing by a trained health worker*

FACILITATOR SKILLS

As a facilitator, one needs to be well equipped with skills to ensure that sessions are conducted successfully. Some of these skills include;

Tact

The facilitator should be tactful when dealing with uncomfortable situations. For example, when the discussion is being dominated by one person, the facilitator can ask everyone to write down their ideas and share with everyone after 2 minutes.

Unbiased engagement

The facilitator should uphold equity in the session by ensuring work is equally and appropriately delegated. No individual or group should be assigned more work than the other. Closely related to this is, the facilitator should avoid expressing their personal opinions more often than the participants.

Good questioning skills

To have a productive session, questioning skills of a facilitator are expected to;

i. *Be structured* - In a way that the audience understands the rationale of each question for example the facilitator can say, 'In order for us to understand stigma....'

ii. *Incorporate silence* - Pauses of at least 3 seconds before inviting responses will give emphasis to questions and allow the participants to gather thoughts before responding.

iii. *Encourage participation* - The facilitator can redirect a question from an active member to a less active member. This should be done cautiously to encourage but not to force a response.

Use of friendly language

Language can affect how a person responds to treatment. While it is important to correct a negative/unacceptable responses in a session, facilitators should void statements such as "*but*", "*you should not*", "*that is wrong"* and but rather use statements like "*remember to...*", "*do not forget to...*", "*another idea would be to....*", at the same time acknowledging a positive response with a labeled praise such as "*thank you for describing how one would approach these issues*".

FACILITATOR SKILLS

As a facilitator, one needs to be well equipped with skills to ensure that sessions are conducted successfully. Some of these skills include;

Establishing ground rules

This will help establish agreeable behaviours during the sessions. These rules include;

i. Participants will not interrupt one another.

ii. Participants will not engage in side discussions.

iii. Silence is considered agreement with the decision to be made.

iv. Participants can disagree with each other.

v. If a decision is reached by consensus, then all members act united to support decision.

vi. There is no wrong answer.

Use a variety of activities

The facilitator could use different layouts for different activities. For example using flip charts to deliver information, ice breakers to reduce monotony, working in pairs or trios.

Question types and techniques

Process questions **-** These will encourage more thought and analysis. For example, the facilitator can ask, 'as a community health worker, what skills can you bring to ensure this project is a success?

Recall questions **-** *These will prompt the participants to remember what happened in the previous session or segment of a session. This will be useful in the recap sessions where one may need to track progress.*

Leading or loaded questions **-** These lead to a more accurate and a balanced answer. For example, *'Do you still perform your monthly check ups on your families?* Or *'You do record your sessions, don't you?'*

Rhetorical questions **-** These help to promote thought and keep attention. For example, we don't want low ratings, do we?

Funneling **-** Is a questioning technique where the facilitator begins with open ended (broadly answered) questions and ending with closed ended questions (more restrictive and focused).

For example;

Facilitator: How was the first session?

CHV: It was great.

Facilitator: What exactly was great about the session?

↓ More focused

EXERCISE AND DIET CONSIDERATIONS FOR PEOPLE LIVING WITH DEMENTIA TO LIVE HEALTHY LIVES

Exercise consideration for people living with dementia

As people get older and have difficulties with their memory, it is common for them to participate in less physical activity. This may be because they are physically frail, or feel that they are not able to participate at the same level as before.

Exercise has a range of benefits to people's health. It is therefore important to remain physically active, even if they are not as fast or as good as they used to be.

Outside of potential health benefits, physical activity can be an enjoyable activity and provides purpose to the individual. Depending on the activity, it may also act as a way of stimulating them socially and cognitively.

Remember that physical activity can come in many forms, even if they may not be seen as exercise. Gardening, dance and household chores all involve an element of physical activity.

Ensure that the person is well supported to participate in physical activities safely. Remember that messages such as "*be careful*" and "*don't overdo it*" can dissuade people to be active.

There is no definitive answer as to how much exercise a person should do. More moderate-to-intense physical activity, that causes elevated heart rate and breathing, may have additional health benefits. However, the key message should be "*something is better than nothing*".

EXERCISE AND DIET CONSIDERATIONS FOR PEOPLE LIVING WITH DEMENTIA TO LIVE HEALTHY LIVES

Diet consideration for people living with dementia

People's nutritional needs can all be met by eating a balanced and healthy diet which is important to ensure that people receive the right nutrients and remain healthy.

If a person is deficient in certain nutrients, it can lead to cognitive problems.

A Mediterranean diet is suggested as being one of the healthiest diets to adhere to. Typically, this diet is high in vegetables, fruits, legumes, nuts, beans, cereals, grains, fish, and unsaturated fats such as olive oil. It usually includes a low intake of meat and dairy foods.

Ensuring that the person has variation in their diet is the best way to minimize the chances of missing these essential nutrients important for the brain.

Remember that a high calorie diet can lead to obesity and other vascular health problems (e.g., diabetes). Poor vascular health can have a detrimental effect on the brain.

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