Dementia in Zimbabwe: Perceptions, Issues, and Inclusion

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DOI: https://dx.doi.org/10.47772/IJRISS.2023.7012010

Received: 07 September 2023; Revised: 21 September 2023; Accepted: 25 September 2023; Published: 28 December 2023

ABSTRACT

Globally, dementia is common mainly among the aged population. While dementia is a worldwide problem, there are diverse issues relating to perceptions and the resultant care for and inclusion of people with the condition, particularly in developing countries. People in all societies are influenced by cultural beliefs, norms, values and traditions to understand and respond to both social and biomedical problems. In this context, the paper explores the perceptions of people in both rural and urban areas of Zimbabwe pertaining to awareness of and sensitivity to dementia, the attendant issues and inclusive practices relating specifically to dementia. Using qualitative-dominant methodology to guarantee in-depth understanding, the paper gives primacy to various categories of participants including people with dementia, their relatives, caregivers, community members and leaders, and policy makers. The central findings are that there are enduring knowledge gaps relating to dementia and how to care for dementia patients; culture shapes perceptions on dementia and the resultant interaction with and acceptance of dementia patients; and that inclusion of people with dementia is largely low. Accordingly, the paper advances new scholarly thinking and practice for a culture and heritage of inclusion where people with dementia have guaranteed access to their fundamental rights, freedoms and benefits.

Key words: culture, dementia, inclusion, society, Zimbabwe

INTRODUCTION

Dementia is a term that is not accurately understood by many people in the communities. In most cases it is misinterpreted to the disadvantage of those who need assistance. Family members and care givers find themselves in extremely difficult situations when they must care for family members in this situation. In some cases, those with the condition are accused of pretending to be sick which may not be the situation at all. Sometimes they are accused of attention seeking behavior. Those with some knowledge about the condition may also not have accurate information. In essence, there are so many misconceptions and myths about Dementia. People in all societies are influenced by cultural beliefs, norms values and traditions to understand and respond to both the social and biomedical aspects of Dementia. This paper is therefore critical to a diverse range of stakeholders, namely persons with Dementia, caregivers, government Ministries, and departments, non-governmental organizations, and other civic society organizations such as churches and Community Leaders. It is intended to shed light on the issues and details surrounding understanding and management of this condition.

Purpose of the study

- To improve awareness and inclusion of persons with Dementia in the communities they live in.

Objectives of the study

- To create community awareness on the specific needs of people with Dementia.
- To help correct myths and misconceptions about Dementia in the communities.
- To support care givers and family members of people with Dementia with information on managing the condition.
- To complement community efforts on how best to identify indications of Dementia with a view to an informed understanding of the condition.

Research questions

- To what extent are the communities aware of information on Dementia
- Which myths and misconceptions needed to be corrected on Dementia
- How best can care givers and family members be supported in managing Dementia?
- How can communities be empowered to identify Dementia.

Statement of the Problem

- To what extent have issues relating to Dementia as a condition been understood by the generality of people in society for purposes of inclusion.

BACKGROUND ISSUES AND LITERATURE REVIEW

In Zimbabwe, the estimated number of people with Dementia is 18000. (Ministry of Health and Child Care Report on Dementia in Zimbabwe, (2018). On the other hand, according to The Global Burden on Disease, (2019) approximately, the number of people with Dementia would increase from 57.4 million cases globally in 2019 to 152.8 (130.8 – 175.9) million cases in 2050. Other statistics also indicate that 55 million people live with Dementia in the world and 10 million cases are recorded every year. (Centers for Disease Control and Prevention, 2019) In addition, Dementia has been ranked as the seventh leading cause of death in the world. (dementia.html). Against the backdrop of such high statistics, it is imperative to understand this condition from an informed position.

Alois Alzheimer, a German Physician pioneered diagnosis and research on Dementia. Cohen -Mansfield, (2000) identified the biomedical mode, a psychosocial model, a disability model and a social gerontological model all of which played a key role in fostering an understanding of Dementia.

Dementia is not a specific disease as erroneously believed and understood by many people. It is rather a general term for the impaired ability to remember, think, or make decisions that interfere with doing everyday activities. (Centre for Disease Control & Prevention, (CDCP) (2019) @what% 20 dementia cdchtml.) It mostly affects older people. It has far reached physical, psychological and social and economic implications to families and society as whole. (Centre for Disease Control and Prevention, 2019) It is also a leading cause of disability and dependency among older people. Dementia has been defined as a syndrome in which there is deterioration in the cognitive function beyond what might be expected from the usual consequences of biological ageing. (dementia.html) The World Health Organization (WHO) recognized Dementia as a public Health priority. In 2017 the World Health Assembly endorsed the Global Action Plan on the public health response to Dementia 2017 – 2025, targeting policymakers, international, regional, and national partners. A Global Dementia Observatory was also set up for policy makers and researchers to promote monitoring. From 65 years of age and above, it was estimated that 5.0 million adults had Dementia

Some Myths and Facts on Dementia

- Timely diagnosis can help delay degeneration.
- Engaging the patient in mind stimulation activity helps delay progression.
- A person can be encouraged to use the active faculties.
- Some forms of Dementia are reversible e.g., Korsakoff syndrome, traumatic brain injury, normal pressure Hydrocephalus.
- Alzheimer is a progressive terminal condition and can't be reversed.
- Medicines help for behavior management only in the initial to the moderate stage.

Source: Sam Yedina Senior Care @www.samvedna.acare.com.

What Increases the risk of Dementia?

Generally, several factors can increase the risk of Dementia. Some of these factors include one's age, poor heart health, high blood pressure, high cholesterol. Smoking also increases the risk of Dementia. Another factor is that of traumatic brain injury. Head injuries in particular increase the risk if they are severe. Other risk factors include harmful use of alcohol, uncontrolled weight, and blood sugar levels. (dementia.html) People also need to guard against depression and isolation. A poor diet can also be a risk factor.

Common signs and symptoms of Dementia

At a basic level, early memory changes and signs could entail misplacing keys, struggling to find a word, but remember it much later or forgetting the name of an acquaintance. There are several signs and symptoms or indicators of Dementia. Basically, people with Dementia undergo three stages in terms of the signs and symptoms namely, the Early stage, the Middle Stage, and the Late stage. One of these early signs is that one may get lost even in a familiar environment or neighborhood. According to the CDCP (2019) people with Dementia are also in the habit of forgetting names of close family members. They are also unable to complete tasks independently. Another factor is that they may also begin to use unusual words to refer to familiar objects. They usual remain with old memories and also tend to easily forget the current information. This keeps them asking one same question now and again. Such people can also lose track of time. As the problem progresses, to the middle stage, they begin to forget recent events. Difficulties in communication are also other common symptoms. Behavior changes also begin to crop in, in addition to wandering and repeated questioning. At home, generally there is confusion. They also develop Agnosia which is the inability to identify objects or persons in addition to having a metallic taste in the mouth, as well as a decrease in the sense of smell.

At the advanced stages, people with Dementia can't recognize relatives and friends. Unawareness of time and place concepts also creeps in. The most difficult challenge can come in the form of inability to walk on their own. Behavior changes increase at a faster pace and aggression also becomes a reality. At advanced stages, the need for assisted care also increases. However, there is no definite way or stages through which everyone with this condition passes through. Situations differ with different individuals and their conditions. No single way will apply to everyone.

Common types of Dementia

Alzheimer's Disease

This section will focus on six common types of Dementia. The first one is Alzheimer's disease. About 60 – 80 % of cases of Alzheimer are caused by changes in the brain (Alzheimer's disease fact national institute

20 aging.html) Heredity plays a key part on Alzheimer's disease with the failure to remember accounting for the better part of this condition. Remembering more distant events mainly occurs at a later stage.

Vascular Dementia

Another common type is Vascular Dementia. About ten percent of Dementia cases are linked to strokes and blood flow to the brain. CDCP (2019) Diabetes, high cholesterol, and Blood Pressure are risk factors with Vascular Dementia. Symptoms may vary depending on the area and size of the brain that has been affected. If more strokes are experienced, the symptoms also get worse.

Body Dementia

Body Dementia is the third type. Memory loss is a major factor on this one. Balance problems such as stiffness and trembling are also common. CDCP, (2019) There is also confusion, unintended sleeping during the day, and visual hallucinations are also common. People and objects that are not there can also be seen by an individual with this type of Dementia.

Mixed Dementia

There is also mixed Dementia. More than one type of Dementia can be present in the brain, especially for those who are 80 years and above. This type is characterized by difficulties in distinguishing dominant types. Progression is faster with one type than the other.

Fronto-temporal Dementia

The fifth type is the Fronto-temporal Dementia. This one leads to changes in the personality of the individual and behavior mainly because of the part of the brain it affects. Those with this condition may embarrass themselves or may make uncalled for offensive statements. (There can also be problems with language skills especially when it comes to speaking and understanding. (dementia.ahtml)

Reversible Causes

The last one involves Reversible causes. This one has a lot to do with the underlying cause such as the effect of medication being taken, increased pressure in the brain, vitamin deficiency and thyroid hormone balance. (CDCP 2019)

Treatment of Dementia

Neurodegenerative Dementias have no cure e.g., Alzheimer's disease. (CDCP, 2019). However, medication can assist by protecting the brain or manage symptoms such as anxiety or behavior changes. Leading a healthy lifestyle with regular exercise helps. Eating healthy food is also good. Maintaining good social contacts also helps.

What to do when one suspects Dementia

If one suspects that something is amiss, it will be good to discuss this with the individual concerned, with a view to go and visit a doctor. Early diagnosis prevents a lot of things from happening. Medical, assessment can then be carried out to ascertain the nature of the problem. Families should also come together to decide on how best to help each other and forge the way ahead. Providing appropriate information in appropriate formats such as Braille and enlarged print may be necessary for those with visual impairments is also critical.

General tips for ease of management of Dementia

- If information must be provided in writing, do not assume that everyone can read.
- Keep written information short.
- Be sensitive when using language.
- Chunking information helps.
- Make use of contrasting colors
- Provide information in user friendly formats e.g., Braille, enlarged print audio, video, where necessary
- Avoid assumptions that the person knows about certain things.
- Be patient.
- Consult widely if not sure.
- Consider referrals where necessary.
- Talk to your Counsellor if you have psychological difficulties.
- Relax and when its bedtime it's good to have lowered lights, cool temperature, and no electronic screens.
- Have a lamp that is easy to reach to turn on or off.
- Keep a telephone with emergency numbers by your bedside.

FINDINGS AND DISCUSSION

Major points that came out of the study were that families of people living with dementia were disintegrated as compared to families without people living with dementia. This is caused by perceptions and issues or beliefs by the society. This was supported by Kaplan et al, (2004) who asserts that the nature of the illness triggers divisions in families as there is strain to the closer relatives.

Marelosov, (2020) agreed citing that dementia in Czech Republic has a physical psychological and social impact, not only on people with dementia but also on their career's, families, and society at large. Furthermore, Wiks, (2008) is also of the view that care giving for disability differs with care giving for dementia because dementia incapacitates a patient. Resultantly, family systems are tested, and composure of the family unit disintegrates.

The other major issue that came out of the study was that dementia patients depended greatly on families and on the use of resources than patients with mild cognitive impairment. Of the same view is Mhaka-Mutepfa, (2014) who asserted that in Zimbabwean culture confining a parent or older mental patient to a foster care home is abhorred, thus they greatly depend on family members. In line with this theme, Wiks, (2008) is also of the view that care giving for disability differs with care giving for dementia because dementia incapacitates a patient. Help Age, (2015) supported this outlining that the social nature of African societys places responsibility for care of patients on an entire family, Bevans et al, (2018) in support states that family members are usually at the fore front of taking care of the elderly.

The other main idea that emerged from the study was that the human rights of people living with dementia were upheld regardless of the illness. However, Mubangizi, (2020) disputes this asserting that in Uganda, physical and chemical restraints are used extensively in care homes for older people and in acute-care settings, even when regulations are in place to uphold the rights of people to freedom and choice. Of the same view is Help Age, (2015) which outlines that the social nature of African societies places responsibility for care of patients on an entire family. This leads to human rights misunderstandings between the family and caregiver (Gureje, Kola, Afolabi, Olley, 2008). As people with dementia are frequently denied the basic rights and freedoms available to others as evidenced by the death of a dementia patient in Ghana.

Perceptions that came out of the study centered on a belief in witchcraft causing fear of persons with dementia and their families. Mhaka- Mutepfa, (2014) postulate that dementia in some families is viewed as witchcraft (kuroyiwa/kuloyiwa) where some relatives cast a bad spell on the patient and calling names on them. Mkhonto and Hanssen, (2018) agreed noting that in South Africa, a person with dementia's behavioural expressions may be considered as strange or abnormal by people and are normally ascribed to witchcraft. This is a strong cultural belief in Black South African as well as Zimbabwean culture that resulted in 'witches' being treated with disrespect and violence. This causes a lot of social pressures to the families with the person with dementia. This was supported by Meyers, (2008) who is of the view that caring for a person living with dementia can also cause multiple emotional strain and social pressure on the caregiver.

Another theme that came out of the study was that families of people living with dementia experienced mental health issues in comparison to families without people living with dementia as compared to families without people living with dementia. In support Dambi et al, (2017) notes that there are fears of isolation, fear, fatigue and overwhelming loss of control encountered by caregiver, who are usually family members. Reinforcing this is, Marima et al, (2019; 514) who asserts that the increased demands of care giving negatively impact caregiver's mental health. However, the author counters this stating that, caregivers who receive an adequate amount of social support are likely to adjust better to the care giving role.

A theme that came out of the study was that families implored a number of coping strategies in countering socio economic challenges they faced. Dambi et al, (2017) recorded that in rural Zimbabwe stress and coping strategies include traditional plays conducted at the home of the patient as a way of lifting their spirits and reawakening the jovial past of the family. In Uganda Mubangiz, (2020) states that managing stressful situations can include minimizing, avoiding, tolerating, and accepting the stressful conditions, as well as attempting to master the environment.

CONCLUSION

In conclusion issues discussed included perceptions, issues, inclusion, and the social factors affecting families with patients suffering from dementia, economic factors affecting families with patients suffering from dementia and coping strategies employed by families with patients suffering from dementia.

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