

A qualitative study on caregivers and patients perceptions about Alzheimer's and related dementias in southwestern Uganda

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Abstract

Background

In the treatment and safe service delivery of each disease, it is very important to understand the perceptions of caregivers and patients where they are not well understood because different cultures, regions and ethnicities have different ways how they understand the concept therefore this study aimed at understanding how patients and caregivers perceive Alzheimer's and related dementias and their coping strategies in south western Uganda.

Methods

A qualitative cross sectional study was conducted using purposive sampling and 18 and 12 caregivers and patients were recruited respectively where in-depth interviews were conducted and data was analyzed using ATLAS Ti software.

Results

Five broad themes were used from Kleinmans explanatory model from both 2 objectives which included perceived identity, causes, treatment, effects and coping strategies. Participants had different views about each category. A big number was able to identify the disease as forgetfulness and the perceived causes included physical, psychological, and witch craft and most of caregivers continued to say that this disease does not need treatment since the most cause of it is aging which is a natural process while treatment was only sought secondary after going to the health facility for another cause/disease. The effects on caregivers include strain financial constraint, poor health while patients complained of non-productivity, psychological/emotional torture and lack of independence. In the instance of coping strategies more caregivers had options of seeking help from relatives, community based organizations (CBO) while some had no option but to just believe God.

Conclusion

Study findings reveal that caregivers and patients of Alzheimer's and related dementias have both positive and negative perceptions. The negative perceptions lie more on treatment options and these may affect service delivery and reduce patient's life span when the right treatment is not thought. Therefore continuous community sensitization about the disease is needed more.

Background

Alzheimer's disease is the most common cause of dementia and is an important cause of death and disability amongst individuals in aging population (1) .

According to Alzheimer's disease International, about 47 million people globally are living with Alzheimer's disease and its related dementias (AD/ADRD) of which 58% live in low and middle income

countries (LMICs). It is further projected that this number will almost double every 20 years with an increasing burden in LMICs such that by 2050 these countries will bear 68% of the burden (International World Alzheimer Report 2015)

In Uganda, the population has grown from 9.5 million in 1969 to the current (2019) 40.4 million and its projected to reach 75 million by 2040. Uganda has a population growth rate of 3 per cent per annum and is the third fastest growing population in the world (2). The life expectancy has improved over the years and currently estimated as 64.8 years among females and 60.2 years among males (3). (Uganda Bureau of statistics 2014).

The aging population (60 years and above) is expected to increase and the incidence of Alzheimer's disease is expected to similarly increase. However, there is little information about peoples' perception of the disease in our society today. Perceptions and socio-cultural factors are thought to influence the community's or family's commitment to care (4).

Studies have shown that cultures attribute patients with dementia to be just old and therefore have no contribution to the economic development whereas others perceive them as witches (5). While some caregivers think providing treatment is a waste of time, others associate the disease with normal aging and think with time the patients will recover with no need for support or treatment.(6), Such patients are neglected and die. However, patients with dementia live in fear, lose self-esteem, are embarrassed and feel ashamed because of change of behaviors they encounter when the disease sets in (7). It is also believed that people from different ethnic groups, cultures, those who do not have knowledge about the disease and had never seen such patients especially men and young people, make the situation worse by increasing stigmatizing attitudes towards the patients (8).

Patients with dementia who report of less effective coping strategies have no intervention that can help them continue with life and the caregivers forget that they need help whenever necessary.(9) .

The burden of care for patients with dementia is high for both formal and informal caregivers. As the population grows older the burden of care is expected to increase and as the number of patients with dementia increases, there is increased demand for health service delivery for these patients. However, utilization of health services for every disease is usually determined by people's perception.

Understanding the perception of the caregiver, the patients with dementia may help come up with better remedy that will influence positive attitudes towards screening and care of patients with dementia.

Understanding of these patients and their caregivers perception will help to put measures on how safe self-care and illness management of patients(10) and this would also help the health care professionals with a wider picture on the disease and guidance on the provision of health care that meets individual needs(11). It is also known that people's perceptions about the disease influences patients behavior and outcomes towards the disease (12). Therefore, the study seeks to assess perceptions of caregivers and patients about the causes, treatment, severity, and the outcome and coping strategies of Alzheimer's and related dementias.

Methods

Research design

This was a qualitative cross-sectional study seeking to understand the perceptions of Alzheimer's and Related Dementias

Study Setting

The study was conducted in the month of January 2019 in 2 districts of Southwestern Uganda namely Rukiga and, Rubanda. All the participants were coming from the rural areas. The main socio- economic activity was subsistence farming and the major crops grown were sorghum, sweet and Irish potatoes and peas. The local populations from these regions are composed of the Bakiga, and Banyankole tribes, which share cultural and linguistic roots. The languages most spoken are Rukiga which is dominant followed by Runyankole. The population of Rukiga district is 100,726(Census 2014) while the one of Rubanda is 206,600.

Sampling Strategy

The study districts were purposely selected basing on the age. In 2014 Uganda Bureau of statistics stipulated the region to have the highest number of old people above 60 years. The study participants were also purposely selected due to the presence of two rehabilitation centers for the elderly and those with confirmed Alzheimer's and related dementias by clinicians. Patients and caregivers were interviewed either at the Rehabilitation centers or in their homes. In order to select patients who were able to give meaningful interaction with the research team, a simple screening tool Activities of Daily Living (ADL)was administered and patients with mild to moderate dementia were considered while it was open to caregivers all caregivers of patients with mild, moderate and severe dementia were included.

Study Sample

A total of 33 participants were included (13 patients and 20 caregivers). Caregiver's age ranged from 18 to 70 years and their average mean age was around 40% while Patient's was about 72% and basically 95% of the patients were females while caregivers was 65%. The patients had mild to moderate dementia and aged above 60 years. Patients and caregivers from Rukiga and Rubanda districts were identified through a rehabilitation center for the elderly, Reach One touch One Ministry and Heal Medical Center respectively.

Inclusion and Exclusion Criteria

Elderly people of 60 years and above with dementia and Caregivers who are involved in taking care of the patient for at least one month and above were included in the study while patients with severe form of dementia and caregivers who were below 18 years were excluded.

Data collection

Open ended explanatory of illness interview guide was borrowed from Kleinman's explanatory models (EMS) framework (13) to explore lay perceptions about dementia among patients and caregivers. We used the EMS framework to gain more understanding of what the patient and caregiver perceived dementia. Data for both patients and caregivers was collected through audio recording, observation and writing of notes. It was a face to face interview where each patient and caregiver was asked questions from the guide and their verbal response recorded.

Data quality control

Graduate Research Assistants with knowledge and experience in qualitative as well as ability to speak Runyankore- Rukiga language were recruited and received structured training on human subjects research, basic research methodologies, conducting IDIs, and recording responses. To ensure highest quality of data collection, while interviewers were in the field, they were provided strict on-site supervision and support by the principal investigator. A professional counsellor was recruited among the research assistants to do data collection and then give counselling services to participants.

Data analysis

All data recorded in local language was translated and transcribed. We read through all the transcripts while listening to the audio recordings to clarify data source, get familiarized with the data and confirm the completeness of transcription and accuracy of translation. Samples of transcripts were read in order to develop code list and code definitions. The ATLAS.ti, software for qualitative data management was used to code, and organize data during analysis. Key codes were used to retrieve various segments of the data; the retrieved segments were organized into sub themes. Each sub theme was described and rich verbatim quotes from participants were used to illustrate the findings. The broad themes were borrowed from the explanatory model of illness.

Ethical Consideration

The Mbarara University Research Ethics Committee approved the study while permission was granted by the rehabilitation centers where the patients were traced. Voluntary verbal and written informed consent was obtained from the caregivers. Patients gave assent and caregivers consented on their behalf.

Results

Name/identity of the illness

Participants used two local concepts to describe dementia. The concepts were "Akahugye and kwebwayebwa" which means forgetfulness " okugwejegyera munonga" which can be translated as excessive sleepiness

More than a half of participants identified the disease as disease of forgetfulness noting that people with the disease easily forget things that were important to them including names of loved ones, important

places and directions. Sometimes they do mix up things which may create confusion among the family members especially when it comes to money issues. They think their relatives steal their money when in actual sense these items are normally kept somewhere or a patient can be handling something and laments where she or he could have put it as evidence by quotes from both male and female caregivers

"She certainly started forgetting because when you give her maybe like money, she forgets where she keeps it and we start searching the whole house until we find it. At times she complains that we steal her money which is not true". Caregiver Female 7

"Of recent her grandson called us on phone when I handed the phone to her she asked me what to say" Caregiver male 14

....."You find her carrying rags thinking that it is a baby" Caregiver Female 23

Some called it the disease of excessive sleepiness noting that the patients with symptoms normally dozed off all the time

"In fact I always worry when I leave her alone at home because she may doze while cooking and fall in the burning stove" Caregiver Female 1

Perceived causes of illness

Respondents identified a range of physical, psychological and spiritual explanations to account for causes of dementia

Physical

Identified physical causes included age, excessive alcohol consumption, loss of sight, other physical illnesses like high blood pressure, malaria, extreme sleepiness, and other frequent illnesses, medication side effects of medication and poor feeding.

Most Patients and caregivers acknowledges that as you grow old the brain also grows old and in turn you start forgetting while others think it comes secondary to others illnesses and then poor feeding.

I think it is age and sickness.... even community people tell me that am old that is why am experiencing all this. Patient Female 25

... taking different medications..... I eat poorly I do not eat the food I like. Patient Female 17

Psychological

Identified psychological causes included stress, staying alone, poor health, frequent loss of loved ones like husbands, children, siblings which also contribute to loss of memory. It is believed that having so many thoughts and being alone puts you at a risk of developing dementia and these were pointed out by both patients and caregivers.

"She lost 6 of her children who were already grown up. Since then, she started forgetting" Caregiver Female 23

"Losing my children, you see losing your closest people affects you so much; I lost all my relatives and this has affected my wellbeing" Patient Female 4

Witchcraft

A few respondents, both patients and care givers associated dementia/loss of memory with witchcraft. . They noted that jealousy neighbors and relatives had decided to bewitch the patients and as result the patient had lost memory

"Am thinking that someone bewitched me and that's specifically the root cause of the problem"
Patient Female 16

Perceived appropriate treatment

Participants identified five sources of care that were perceived to be appropriate for patients with memory loss. These included modern medicines, proper feeding and spiritual. However, a substantial proportion of respondents believed that loss of memory was part of normal aging process and therefore required no medical attention.

No need for treatment

Respondents who believed that forgetting was part of normal aging process noted that seeking treatment was a waste of time and resources. They believed that aged people who were losing their memory could benefit more from care and support from home than making them go around hospital since this was a disease of old age.

"Forgetting, I never took her to the hospital. Is there any hospital that cures memory loss? I do not think doctors cure that" Caregiver male 14

"I never got medicine for memory loss there is no medicine for memory loss" Patient Female 17

Medical

A good range of participants believed that this could be treated using modern medicine and indicated to have sought medical treatment.. However most of them indicated that they went to health facilities primarily for physical illnesses that needed urgent attention and forgetting was a secondary reason for the visit. During these visits some of the patients were able to get investigation and diagnosis of dementia.

"The doctor diagnosed her carefully; she was put in scan and even her blood was also tested for malaria but all results came out negative. However the doctor told me she has ulcers and age is

disturbing her the most". Caregiver Female 28

"I went to the hospital for treatment and I am still on treatment otherwise I would be dead by now".
Patient Female 1

Proper feeding

A few respondents believed that forgetting was a result of poor feeding and therefore what people with memory loss needed was proper feeding. Some noted that information about role of diet on memory regeneration was received from both the formal sources such as health workers, and informal sources such as friends, and other community members

"I have majorly ensured proper feeding on her. This is both via eating in time and feeding on the recommended foods"

Spiritual

In addition to other form of care most participants believed that spiritual counseling and prayer was a good for patients with memory loss. It was noted that when patients received prayers from religious leaders made them feel better spiritually

Some responses include

".....I only prayed to God for his mercies; and slowly I started to gain my memory." Patient Female 10

Perceived effect of Memory loss

Participants identified several effects that resulted from having a disease of memory loss or being a person caring for a family member with memory loss. The effects included loss of productivity, failed social responsibilities, Financial constraints for both patients and caregivers, Health of the caregiver and too much burden, Financial loss due to forgetting, Psychological and lack of secrecy.

Productivity

Loss of productivity was identified by most respondents as the most negative effect of dementia. Care givers in particular care had to force themselves and put other activities on hold. Most of caregivers expressed stress related to care giving as these patients were not able to perform any of the activities of daily living such as using the toilet, bathing, washing, cooking.

"She doesn't do anything; ... needs extensive care. This has prompted me to drop much of my day today schedules". Caregiver Female 12

"I do not do anything; In the morning before she goes away, she takes me out side and leave food with me and that is where I remain until she comes back". Patient female 14

Failed Social Responsibilities

Other identified effect of dementia included failing social roles on the part of the patients. Respondents noted that because patients forget things they are were unable to perform the expected roles in their families or community. Some of these roles included failure to care for their loved ones for example taking care of spouses, unable to attend community meetings and functions unable to play their role of transmitting local knowledge such as advising and counseling the younger generation. These failures lead the people with dementia into isolation and finally they are now socially isolated.

"...I cannot execute my obligations as a woman and mother like before." Patient Female 4

"I used to walk slowly and go to the trading center but now I cannot. I keep here all day long alone".
Patient Female 25

Financial constraints for both patients and caregivers

Financial constraint was an effect of dementia that was mentioned by almost all the care givers. Respondents noted that they faced financial problems because they were spending money to care for patients but they were too busy providing care and lacked to make additional money. Some indicated having spent all their saving and had remained empty handed.

...she goes to the trading center alone and gets things from the shop on credit and forgets to tell me. You find people complaining that I do not clear my mother's debts. So her condition has really destroyed my status and has affected my income somehow because I spend where not necessary.
Caregiver Male 10

Poor health

Some respondents noted that care givers were burnt out and experienced poor physical health due to burden of caring for patients with dementia as reported by a patient below

"Both my husband and daughter I disturb them so much. They carry my bucket. They employ house maids but because of my condition, they cannot stay home for long. At times I pray to God to make me rest in peace but it seems my time is not yet". Patient Female 4

"Cleaning her is very challenging, the smell that comes out of her while preparing her is awful and it's making me sick in fact I developed strange cough because of that". Caregiver Female 28

Financial loss due to forgetting

Patients attributed the sickness to have made them loose their money. They said due to memory loss whenever they place their money somewhere it gets lost either it is not found.

If someone comes across it cannot reveal it and then they also have no choice some declare their money to their caregivers when they have wished not because they know that they will forget it where they placed it. Some patients still had a feeling of helping financially to other people and they do not want their caregivers to know because it will create a conflict and others feel that every person should have a secret but since they forget it becomes very difficult hide anything.

"I have lost a lot of money; you know money is very important it even killed Jesus". Patient Female 4

"I cannot keep my money secret. I try to do so I forget where I kept it so am forced to give it to my daughter to keep it for me" Patient Female 17

Psychological

Most patients felt they are not loved; they have lost peace and feel isolated all the time they cannot associate with the rest as they used to do before the sickness set in.

"It has honestly affected my health; I have no peace at all and since there is no treatment for it, I have nothing to do". Patient Female 4

Coping Strategies

Caregivers of patients with dementia use various coping strategies to manage challenges brought by dementia. A number of primary caregivers sought support from other family members in order to avoid burn out; others sought support from the available community based organization, while a few hired caregivers from outside the family network such as household help who support caregivers.

Seeking support from family members

Most caregivers would ask for support from other family members in case they lack money or food and then sometimes other family members come in to give help but this was not a guarantee that they had to receive support immediately, sometimes they turn them down.

"Well our relatives support us a little; once in a while they send some money and foodstuffs but it is me who struggles a lot". Caregiver Female 8

Support sourcing from CBO, and employing caregivers.

Some patients and caregivers appreciated some help from the community based organization (Reach One Touch One (ROTOM) that is in reach for elderly people especially those living with dementia, they said it has helped them in terms of medicines, food stuff and clothing and that's how they sometimes survive while others who can afford have tried to hire some people to look after their patients but in turn it becomes difficult for those people employed and in turn they run away.

"Nothing for sure because I do not have anyone to take care of her such that I can go and earn a living. At times I employ a worker to care for her but due to her condition, the worker runs away".
Caregiver Female 4

"I solely take the responsibility of looking after her with the aid of ROTOM healthy facility which aids in giving health care". Caregiver female 6

No support given/given up

However, a substantial number of patients and caregivers reported lack of reliable social support system. Patients under such circumstances were stressed and felt alone.

"I do not have any support from any one. I was a business person but in this condition I cannot do anything. I have no one to help me and I keep regretting why am in this condition". Patient Female 10

"Though I have relative, I feel like am alone .Patient female 20

The caregivers who had limited source of support felt stressed and burnt out as they struggled to combine care giving and breadwinning roles

"They do not contribute even a coin to care for this patient; they care less about her. Everything is on my head". Caregiver Male 13

Discussion

Summary of the results

The purpose of this study was to assess the caregivers and patients perception of Alzheimer's disease. The main issues to look unto were how the disease is named or identified, what they believe are the causes, treatment, effects, outcome and finally the coping strategies.

Forgetting and sleepiness came out as an identity while physical, psychological, witchcraft stood out to be the most causes. Medical, no need for treatment, proper feeding and spiritual were categorized under treatment.

Effects were categorized as loss of productivity, failed social responsibilities, financial constraints for both patients and caregivers, health of the caregivers and too much burden, financial loss due to forgetting and lack of secrecy and psychological.

The copying strategies were identified as seeking support from family members, no support given, support sourcing from CBO and employing caregivers.

Identity

The most revealing word given to identify the disease was forgetting meaning that most participants know that they forget and to them it seems to be a normal process because they do not attach it to be a disease. This was also found out in a study that was done in Democratic Republic of Congo where most patient with mild to moderate and their caregivers revealed that they mostly forget (14, 15)

Perceived Causes

The most perceived causes of illness identified were physical and psychological of which aging and bereavement/loss of dear ones appeared most. Since dementia has almost the same characteristics of most psychiatric disorders like wondering, forgetting, and hallucinations most caregivers and patients thought that it could somehow be due to psychological problems regardless of putting aging as the first criteria and this is in line with a study done in Brazzaville Republic of Congo (14, 15). However a few believed that it can be due to witch craft where patients specifically attributed it to other people who wished them bad either due to their fame and other social and familial reasons. However this is not so surprising because in African traditional setting almost such diseases are termed as misfortune and in a long run they find themselves seeking advice or treatment from traditional healers and witch doctors

In regard to the perceived causes of the disease participants especially patients were able to identify that the main cause could be aging, poor feeding, alcohol consumption, and other physical diseases which include high blood pressure. Aging appeared to be more common for both patients and caregivers and this is true because they see it is common in elderly people. However, they do not know at which age does it normally happen and also distinguish between what is normal forgetfulness and the abnormal one or the extent to which someone is termed to have a disease (16-19) while others attribute it to witchcraft and this could explain why most of caregivers and patients do not take the disease to be a medical condition and instead they seek other ways of care like spiritual healing and traditional care(17, 19, 20)

Perceived Treatment

There was an agreement in most caregivers that there is no need for treatment since the disease is due to aging and therefore you cannot bring forth back what has been damaged. This could probably explain why they did not seek medical treatment and those who went to seek medical care went with a primary illness contrary to dementia and during the assessment dementia also appeared. This is proven in another study where it was found out that basically people lack specific information and treatment about the condition (21). Surprisingly most patients were contrary to their caregivers they think probably medical treatment could be of more relief or alternatively spiritual consecration that is believing and trusting the almighty God through prayers and being laid of hands upon them by the spiritual elders of which they could be church leaders(20).

Perceived Effects

Perceived effects for caregivers and patients were highlighted as lack of productivity, loss of property especially money and psychological torture and these are perceived to come from caregivers and the

community.

It is believed that having a person with dementia puts more burden on caregivers especially productivity and failed social responsibilities followed by financial constraints this is supported by (14) where the leading consequences/effect was socio economic constraint which includes all the three outstanding parameters of the effect(18)

Caregivers were more concerned about their health which they highlighted as strain, stress depression and poor health and these can lead to decreased care and neglect of such patients (22). It is believed that the caregivers whose services to patients are more often that is on everyday basis faces the mentioned effects compared to the occasion caregivers and this issue was mostly reported by caregivers in our study(23). It is also perceived that care giving leads to physical and emotional strain on caregivers and to the extent of leaving and losing their jobs(24, 25).

Patients were more concerned about their day to day work, loss of independence and psychological torture. This effect does not only affect the patient but also the family. For example where you would find the person has been the bread winner for the family as well as the community in terms of social responsibilities and in a long run they turn out to only depend on these caregivers which could be their spouses children and other relatives or well-wishers. Some people including family members perceived them as witches and others think they might be something wrong they did in order to get such illness and in turn these patients continue to have the psychological torture thinking about how the family and the community at large perceive them. It is not surprising that the above instances were also discovered by (7, 9, 26)

Perceived Coping Strategies

When it came to the coping strategies for both patients and caregivers, almost all patients were looking up to their caregivers as their hope while caregivers thought to get help from their relatives of which it is not a mandatory and some a few organization to those who were near them while the rest had no hope and where to run too.

This too means that there is still a gap in institutionalization in our setting and more so people are not willing to commit themselves fully in taking care of these patients unlike in other settings, countries where the relatives and institution provide more financial, psychological, emotional care to their patients.

This seemed to be contrary to other studies that were done in other countries where there are institutions and relatives who solely take care for such patients.

Limitations

The study was cross sectional in nature and could not capture the thoughts of participants especially caregivers as the disease progresses however some a few that participated who had their patients in a

severe form of the disease could have represented them. The study only looked at caregivers whose patients were alive at the time of inclusion leaving out the caregivers who had lost their dear ones.

Conclusions

The study findings show that there are various perceptions between patients and caregivers. Both were able to identify the disease very well however caregivers expressed some negative perceptions which may affect their ability to seek medical care and hence shorten the life span of their patients. Therefore it is now necessary to create awareness to such population.

Recommendation

There is a need to build an understandable package that will create awareness to the community about the disease such that the negative perceptions are minimized which will create more accessibility of medical care and treatment outcome.

There is also a need for support from the ministry of health to see such illnesses are included in the priority areas and if possible more specialized institutions are built and formal caregivers be put in place to relieve the families, relatives and friends of the affected people.

List Of Abbreviations

AD Alzheimer's disease

ADL Activities of Daily Living

AD/ARDs Alzheimer's disease and Related Dementias

CBO Community Based Organization

EMS Kleinman's Explanatory models framework

LMICs Low- and middle-income countries

MADRI Mbarara Alzheimer's disease and Related Dementias Initiatives

MUST-REC Mbarara University of Science and Technology Research Ethics Committee

NIH National Institute of Health

Declarations

Ethics approval and consent to participate.

The study was approved by Review Ethics Committee Mbarara University of Science and Technology (MUST-REC) in November 2018. All participants including Patients and their caregivers were consented to take part in the research. Patients who had moderate Dementia were assented and their caregivers consented for them.

Consent for publication

Consent from Caregivers of patients with Mild to moderate dementia were assented and consent from their caregivers obtained

Availability of data and materials

Data and materials of this research can be obtain from the corresponding Author on a reasonable request.

Competing interests

The content of this research is solely the responsibility of the research team and researcher herself. Therefore the authors and funders of this research declare that they have no competing interests whatsoever.

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Authors' contributions

All Authors mentioned contributed from the development to final draft of this paper.

The first author JT wrote the manuscript and a draft the rest (ESO, BG, SM, ED) provided guidance and revisions of the manuscript, while CO was the overall supervisor, mentor from the inception of the project to the last part.

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