



**LIVED EXPERIENCE OF CARE GIVERS OF PEOPLE WITH DEMENTIA (MAJOR
NEURO COGNITIVE DISORDER) IN ADDIS ABABA: A QUALITATIVE STUDY**

A final research report submitted to the department of Psychiatry, School of
Medicine, College of health science, Addis Ababa University, in partial fulfillment
of the requirements for the specialty certificate in Psychiatry.

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ABSTRACT

Introduction

Dementia is a multifactorial syndrome characterized by Impairment in memory, communication, judgment, orientation, problem solving and cognition. People with dementia require increasing amounts of assistance in activities of daily living and behavioral symptoms. In low income countries most of the assistance is provided by informal care givers. There is no available study on care givers of dementia patients and their lived experience.

Objective

To explore and describe lived experience of care givers of people living with dementia.

Method

A qualitative research design was used. Participants were recruited using purposive sampling. Sampling was until theoretical saturation is achieved. Six in depth interviews were done. The interviews were audio recorded, transcribed in Amharic and translated in English. Thematic analysis was used to identify key themes.

Results

The major findings from this study are care givers lack understanding about the diagnosis of dementia .Care givers day to day life is filled with assisting their care recipients and dealing with problematic behaviors. Negative emotional states and financial problems were raised in association with care giving process. They tend to be more involved in religious activities and seek help from other family members to deal with the challenges.

Title of the study

**LIVED EXPERIENCE OF CARE GIVERS OF PEOPLE WITH
DEMENTIA (MAJOR NEURO COGNITIVE DISORDER) IN ADDIS
ABABA: A QUALITATIVE STUDY**

ACRONYMS

AAU Addis Ababa University

BPSD Behavioral and Psychological symptoms of dementia

WHO World health Organization

ZMH Zewditu Memorial Hospital

Introduction

Dementia is a multifactorial syndrome characterized by impairments in memory, communication, judgment, orientation, cognition and problem solving. (Sadock, Sadock, & Ruiz, 2017). It causes irreversible decline in social, cognitive and physical function (Wang, Sheng, Fan, Zhang, & Xu, 2019). Alzheimer disease is the most common form of dementia and contributes to 60-70% of the cases (WHO, 2019). There are also other forms of dementia like vascular dementia, frontotemporal dementia, dementia with Lewy bodies. Dementia can also be caused by different medical, neurological conditions or various substances (Sadock, Sadock, & Ruiz, 2017)

Dementia is one of the major global health care challenge affecting 50 million people worldwide and it is the fourth leading cause of disease burden in high income countries (WHO, 2019).

According to a systematic analysis done in 2012, the estimated prevalence of dementia in Africa was 2.4% and approximately 2.76 million people are living with the syndrome (George-Carey, et al., 2012). The same analysis showed that majority of people with dementia is living in sub Saharan Africa (George-Carey, et al., 2012). There is no study done showing the prevalence of dementia in Ethiopia, but according to WHO data published in 2017, deaths related to dementia reached 0.94% of total deaths, making dementia 18th leading cause of death in Ethiopia [world health ranking].

People with dementia require increasing amounts of assistance with activities of daily living and behavioral problems (Daley, et al., 2018). Most of the assistance is provided by family (CHIUNG-YU HUANG, 2006). In low income countries where the care is mainly provided by informal care givers makes the situation even worse (Daley, et al., 2018).

According to Pearlin 'Caring is the affective component of one's commitment to the welfare of another, whereas Care giving is the behavioral expression of this commitment' (Pearlin, Mullan, Semple, & Skaff, 1990). Informal care giving differs from formal which is done by trained and employed health workers, by the

fact that it is based on emotional connection, family ties and it is not time limited (Pearlin, Mullan, Semple, & Skaff, 1990).

In low income countries most care giving is provided by informal care givers (Prince, et al., 2012) and many studies showed that behavioral and psychological symptoms of dementia (BPSD) are one of the major causes of care giver burden (Prince, et al., 2012).

Multiple studies showed that informal care givers experience physical, psychological and financial problems during the care giving process (Maayan N, 2014). In addition decreased time for self-care and poor social interaction are part of their problems. (Moyle, et al., 2011)

Care givers use different coping mechanisms in dealing with the challenges. A study done in 2006 showed that effective coping strategies are helpful in decreasing care giver burden, anxiety and depression (CHIUNG-YU HUANG, 2006).

Rationale of the study

Several studies showed that the number of people living with dementia is rapidly increasing in Sub-Saharan Africa. Due to the nature of the syndrome, patients with dementia require increased amount of assistance. Most of the assistance is provided by close family members.

There are many studies which focus on lived experience and quality of life of care givers of dementia in developed countries. However the studies are very few in Africa. There is no study done in Ethiopia about the lived experience of care givers of dementia.

Many studies showed that support for care givers is an important strategy in dementia care. Since informal care givers are the ones that are involved in the care giving process, understanding the care givers experience in the local context is very important to explore the needs of the care givers, gaps in the health

service and in general in designing strategies targeting well-being of people with dementia and their care givers.

Research questions

- What is the day to day experience of care givers of dementia patients?
- What is the psychosocial impact of care-giving?
- How is coping in care givers of dementia patients?

Objectives

General objectives

- To explore and describe the lived experience of care givers of dementia patients.

Specific objectives

- Describe the day to day experience of care giving.
- Explore care givers burden.
- Explore the Psychosocial impact of care giving.
- Explore care givers coping.

Methodology

Study setting

The study was conducted in Zewditu Memorial hospital which is located in the capital city Addis Abeba. ZMH was established by Emperor Haileselassie with the cooperation of Swedish missionary doctors (Seventh day Adventist church) in 1971 (Lohne, 1971). In addition to other services the hospital provides in-patient and outpatient Psychiatric care. The Psychiatry case team consists of 2 consultant Psychiatrists, 3-4 Psychiatry residents, 5 mental health professionals. Patients with dementia are seen in regular Psychiatry OPD. Currently there are 15 Dementia patients who are on follow up at the OPD.

Study design

- Exploratory qualitative study design was used.

Study population

- All primary care givers of dementia patients currently on follow up at ZMH.

Sampling

- Purposive sampling was used.

Inclusion criteria

- Care givers of patients with documented clinical diagnosis of major neurocognitive disorder and who consented to participate in the study.
- Care givers that can speak Amharic.

Exclusion criteria

- Primary care givers who can't speak Amharic and who were not willing to participate in the study.

Sample size and data collection

Patients with dementia were identified from the record available at the OPD. The care givers were initially contacted by a phone call and explained about the study and arranged time for the interview at the OPD. Written informed consent was obtained. For the care givers who can't read, the information sheet was read out loud and finger print taken. Sampling continued until theoretical saturation was reached. Six participants were interviewed in quite room in the afternoon.

All interviews were conducted by the researcher in Amharic. After introduction and reading out the information sheet, all were asked to sign the consent form. Ethical clearance was obtained from AAU Psychiatry department and ZMH. All of the interviews were conducted at Zewditu hospital psychiatry OPD during the afternoons. Nobody opted out of audio record. Each interview lasted from 30 min to 1 hr. All the records were transcribed and translated to English.

Analysis

The audio recording was transcribed and translated. The whole document was read repeatedly and first impressions were jotted down. Then coding was started using opencode software version 4.03. Important themes were generated by inductive thematic analysis.

Results

Socio-demographic characteristics of the participants

Participant number	Age	Sex	Relationship with the patient	Religion	Education	Job
001	38	F	Daughter	Muslim	Primary school	Unemployed
002	55	F	Wife	Orthodox Christian	Uneducated	Unemployed
003	34	M	Son	Orthodox Christian	First degree	Unemployed
004	45	F	Daughter	Orthodox Christian	Secondary school	Unemployed
005	50	F	Wife	Orthodox Christian	First degree	Secretary
006	68	F	Wife	Orthodox Christian	Uneducated	Unemployed

- The findings are presented in four themes
 - Understanding about the diagnosis,
 - Problematic behaviors of care recipients are difficult to handle,
 - Impact of care giving and
 - Coping strategy.

Understanding about the diagnosis

All care givers agreed that their care recipients have some kind of mental health problem but there were differences in their understanding about the problem. Most participants described the behavioral and psychological symptoms as related to mental health problem. Two of the participants were able to associate the forgetfulness and BPSD as one illness. And they call the problem 'yemersat Beshita'. Whereas other participants gave different expressions for the problem like 'rasun yasitewa' (he is not with his self).

After probing all of the participants were able to describe about the forgetfulness. However there were different views in their explanatory models. One care giver stated that his mother's problem is associated with evil spirit.

'I think it is associated with religion. She recently became nun and Satan is challenging her, I believe it is this evil spirit that results in her condition. We usually takes her to holy water place, the reason I started follow up here was because she started shouting at night and began disturbing neighbors.'

Another care giver stated that it is associated with normal aging. Other care giver whose husband had diagnosis of stroke and stated

'My husband had a nerve illness and now it is changed into a mental illness because of aging.'

Most of them reported that they haven't got enough information from the physicians during follow up visits.

Problematic behaviors of care recipients are difficult to handle

All care givers reported that their family members show different problematic behaviors like urge to be on the move, problems in activities of daily living like feeding, bathing, toileting...., problems in sleep, aggression, and suspiciousness are the major problems they are facing. Care giving for patients with dementia is

very difficult and demanding .One of the care givers shares the following: *'One day when I got home from outside, the floor was contaminated by her urine and my mom was pouring water on sofa, sometimes I feel like I am raising a child'*.

Most of the care givers mentioned that these behaviors are significantly affecting their lives than the problem of forgetfulness. One care giver mentioned that her mother no longer remembers her but the presence of these behaviors makes her life tough. The need to be always available for the care recipients are another important factor that was reported by the care givers.

Impact of care giving

Most of the care givers reported negative psychological states like low mood, anxiety, guilt and irritability. One care giver reported that: *'it is hard, these days I even feel like what they call depression I feel low most of the time, the fact that my mother hasn't improved disturbs me'*.

The following quote illustrates one care giver's experience as a primary care giver of her mother.

'Sometimes I get irritable and ask God to take her then I felt guilty and prey God for mercy'.

Not all care givers have negative emotional states, one care giver states that care giving for her husband is a positive experience for her. She described that care giving is a way of returning the great things that her husband helped her to achieve in the past.

Financial impact of care giving is raised by almost all participants. Most of the participants stopped working to help their family members, which made them economically dependent on their children or relatives. Another care giver was forced to hire a house maid.

Coping strategy

The participants describe different ways of handling the problems they are facing. Most participants reported religiosity as an important factor in reducing their stress. One participant described that she became more involved in religious activities and it is helping her very much. She shares her experience as:

'I read a bible, go to church and pray a lot, especially if my husband wakes up at night I pray even after he goes back to sleep'.

Three of the participants reported that the support and recognition they got from other family members were very helpful for them as a result they tend to seek help when they need one. One of the care givers mentioned that thinking about the good old memories that she spent with her husband makes her strong.

Discussion

In this qualitative study the lived experience of care givers of people with dementia was explored. The study identified four major themes not knowing the diagnosis, problematic behavior of the cases, impact of the problem on care givers and coping strategy.

There seems to be a gap in the understanding about the nature and consequence of the diagnosis. Most of the participants think the behavioral and psychological symptoms were related to mental illness while the forgetfulness is associated with normal aging. This might be due to the general perception of mental illness is associated with overt behavioral symptoms like aggression, agitation, nakedness etc. This is consistent with the report from a Butajira study on perception of mental illness where key informants gave only signs of blatant psychotic disturbance when they were asked how they would recognize a person with mental illness (Alem, Jacobsson, & Araya, 1999). The gap in understanding the diagnosis and lack of information about the problem might be due to poor communication between clinicians and care givers and absence of

psychoeducation during follow up visits. A qualitative study done in London which assessed how understanding of dementia diagnosis impacts care giving experience found out that there is lack of information about the diagnosis (Stokes, Combes, & Stokes, 2014). The authors suggested that greater understanding of the condition is helpful for care givers and care recipients as well (Stokes, Combes, & Stokes, 2014). A similar study done in Hong Kong found out that there is confusion and lack of information regarding the diagnosis (Chan, Ng, Mok, Wong, Pang, & Chiu, 2010).

Behavioral and psychological symptoms are commonly seen in patients with dementia. These symptoms can occur at any stage and are one of the major causes of care giver burden (Ainslea J. Cross, 2018). In this study all participants described that problematic behaviors are very difficult to handle. Problems in activities of daily living (ADL), sleep related problems, aggression and suspiciousness were the symptoms raised by the participants. Most participants reported facing these problematic behaviors as their day to day experience. Similar findings were reported from a study done in Singapore (Tuomola, Soon, Fisher, & Yap, 2016).

When it comes to impact of care giving on the care givers themselves psychological and financial impact was mainly raised by most of the participants. They stated that they experience depression, irritability, guilt and anger. The analysis found out most of the participants experience negative emotional states. These negative emotional states might be due to the overwhelming stress associated with BPSD or due to the cognitive symptom of dementia. However one of the participants described the care giving as positive experience and way of giving her respect for her husband.

Financial impact of care giving was also raised by the care givers as most of the participants described that they needed to stop their work to care for their family members. In addition those care recipients with late stages of dementia required increased assistance. One of the care givers mentioned that expenses for adult diaper are very expensive.

The study also showed that care givers use different coping mechanisms. Most of the care givers use religiosity as a coping mechanism. They stated that they usually go to religious worship places to pray. One of the care givers mentioned that she became more involved in religious activities after the diagnosis of dementia. She also stated that praying makes her strong. In Ethiopian society where most people are followers of Islam or Christianity there is strong connection to religion.

Participants also mentioned the strong support that they receive from other family members was very helpful for them. According to Pearlin's stress model family plays a great role in the care giving process (Pearlin, Mullan, Semple, & Skaff, 1990). Lack of support and acknowledgment from other family members is associated with increased stress in care givers (Wang, Sheng, Fan, Zhang, & Xu, 2019). In this study only two of the participants reported receiving support from other family members and seeking help from them when they needed it.

Limitations of the study

Lack of diversity of the participants may limit the findings from the analysis.

Recommendations

Proper information and Psychoeducation about the diagnosis course, prognosis and outcome for the care givers.

Assessing primary care givers mental health should be part of dementia medical care provision.

Designing effective strategies targeted toward care givers like providing nursing homes would be the right future direction in the country.

Future research is recommended on dementia and its care as life expectancy in the country is increasingly getting better.

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APPENDIX

የተሳታፊዎች መረጃ

እድሜ:

ጾታ:

ሃይማኖት:

የትምህርት ደረጃ:

ሥራ :

የመኖሪያ አድራሻ:

1. ከታካሚው ጋር ያላችሁ ዝምድና ምንድነው?
2. ታካሚው ያለባቸው የጤና ችግር ወይም ህመም ምን ይመስልዎታል?
3. ስለዚህ የጤና ችግር ወይም ህመም ከዚህ በፊት ሰምተው ያውቃሉ?
4. ታካሚው የባህሪ ለውጥ ወይም የህመም ምልክቶችን ማሳየት ከጀመሩ ከምን ያህል ጊዜ በኋላ ወደ ሆስፒታል መጡ?
5. ስለ ህመሙ እና ማድረግ ወይም መስጠት ስለሚቻለው ህክምና ማብራሪያ ተሰጥተዎት ያውቃል?
6. ስለ ታካሚው ህመም መረጃ ካለዎት መጀመሪያ ሲነገርዎት ምን ተሰማዎት?
7. ህመሙን ሙሉ በሙሉ ማዳን የሚቻል ይመስልዎታል?
8. ታካሚውን መንከባከብ ወይም መርዳት ከጀመሩ ምን ያህል ጊዜ ሆነዎት?
9. ባለቤትዎ በዚህ ህመም ከተያዙ በኋላ ከእርሳቸው ጋር ያለዎት የትዳር ህይወት ምን ይመስላል?
10. ታካሚው በዚህ ህመም ከተያዙ በኋላ ህይወትዎ ወይም ኑሮዎ ምን ይመስላል/ ህይወትዎ ወይም ኑሮዎ ላይ ያመጣው ለውጥ እንዴት ነው?
11. ለራስዎ ጊዜ ይሰጣሉ?
መልስዎ አዎ ከሆነ እራስዎን ለመጠበቅ ምን ያደርጋሉ(አብራራ).....

መልስዎ አልሰጥም ከሆነ (ምን ምን ነገሮች ገደብዎት)፤ ምን ምን ነገሮች ቢሻሻሉ ይላሉ

ስልጠናስ ያስፈልጋል ይላሉ

12. ታካሚውን በዋነኝነት የሚንከባከቡት እርስዎ እንደመሆንዎ መጠን በየአለቱ የሚያጋጥምዎትን ችግሮች/ፈተናዎች እንዴት ነው የሚወጧቸው? በአጠቃላይ ለታካሚው እንክብካቤ ከመስጠትዎ ጋር ተያይዞ የሚመጡ ጫናዎችን እንዴት ነው የሚቋቋሟቸው?

13. አስቸጋሪ ነገሮች በሚያገጥምዎት ጊዜ ስሜትዎትን የሚያካፍሉት ወይም የሚያማክሩት ሰው አለዎት ?

14. ከቤተሰብዎ ወይም ከጓደኞቹዎ ውጪ ማንኛውንም ድጋፍ የሚያደርግልዎት አካል አለ

15. በአሁኑ ሰዓት ምን አይነት እርዳታ ቢያገኙ ታማሚውን በተሻለ ሁኔታ ለመርዳት ያስችለኛል ብለው ያስባሉ

16. እርስዎ ከሚያስታምሙት ሰው ጋር ተመሳሳይ ህመም ያለው ሰው ያውቀሉ

17. እነዚህን እርስዎ ለታማሚው እንክብካቤ በመስጠትዎ ወይም አስታማሚ በመሆንዎ ምክንያት ሊመጡ የሚችሉ ችግሮችን ቢያብራሩልኝ

ሀ. ያመጡብዎት ስነ ልቦናዊ ተጽዕኖ ካለ

ለ. ኢኮኖሚያዊ ተጽዕኖ ካለ

ሐ. አካላዊ የጤና ችግር ካለ

18. አንዳንድ አስታማሚዎች/ ለቤተሰብ አባል በዋነኝነት እንክብካቤ የሚያደርጉ ሰዎች የሚከተሉትን ሀሳቦች ያነሳሉ እርስዎስ ምን ይላሉ

ሀ. ነጻ በሆንኩ እና የራሴን ህይወት በመራሁ ብለው ይመኛሉ

ለ. በዘመዴ/በባለበቴ ህመም ምክንያት ታስሬ ቀርቻለሁ ብለው ያስባሉ

ሐ. ከዚህ ህይወት ወስጥ አምልጬ ብጠፋ ብለው ይመኛሉ

19. ዘመድዎን ወይም የትዳር አጋርዎን በማስታመም/ በመንከባከብዎ ያገኙት አስደሳች ነገር/እንደ ሽልማት የሚቀጥሩት ነገር ምንድነው

20. ዘመድዎን / የትዳር አጋርዎን በማስታመም ውስጥ ያለው ፈተና / አስቸጋሪ ነገር ምንድነው