Master's thesis

NTNU
Norwegian University of Science and Technology
Faculty of Medicine and Health Sciences
Department of Public Health and Nursing

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EXPERIENCE OF CAREGIVERS WHILE CARING FOR A PERSON WITH DEMENTIA ATTENDING BUTABIKA HOSPITAL, UGANDA

Master's thesis in Global Health
Supervisor: Prof. Gørill Haugan, PhD
Co-supervisor: Dr. James Mugisha, PhD
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Acknowledgments

Three years, three continents and a pandemic. Reaching the finish line is an unspeakable feeling. More than reaching the three MSc letters, the conclusion of this study is the symbol of a hidden force stemming from different actors.

First, I thank God who, according to my personal faith, gave me the gifts of life and thinking creatively.

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OPERATIONAL DEFINITIONS

Dementia:

A clinical syndrome of decline in one or more cognitive domains from previous level of performance that is severe enough to interfere with independence in daily life activities.

Caregiver:

Any person who cares for an individual with dementia most of the day at home. They provide emotional and physical support for patients and often play a central role in clinical decision-making. For this study, it means someone who has been living with a person with dementia for a period of a minimum of six month or since the start of the symptoms.

LIST OF ACRONYMS

PwD – Person with Dementia

WHO – World Health Organization

NCD - Neurocognitive deficits

QoL – Quality of Life

GP – General Practitioner

CG – Caregiver

NCs - Nonprofessional caregivers

ADL - Activities of daily living

APA- American Psychiatric Association

SOPs - Standard Operating Procedures

NTNU- Norwegian University of Science and Technology.

ABSTRACT

Background: The experience of falling ill can many times be challenging not just to the person directly affected by the disease, but also to those involved in the process, for example, relatives, caregivers, and other people living with this person. Caregivers will most likely experience social restrictions, financial strain, and emotional distress.

Objective: This project aims to understand the experience of taking care of elders living with dementia at Butabika National Referral Hospital, outpatient clinic in Kampala, Uganda.

Methods: This was a qualitative descriptive study. Fifteen caregivers of a person with dementia (PwD) were purposively sampled from the outpatient department of Butabika Hospital, Uganda. Following informed consent, each caregiver engaged in an interview guided by a semi-structured interview guide to obtain information on their experience in caring for an individual with dementia. The information gathered was then organized and analyzed through a qualitative content analysis framework inspired by Graneheim and Lundman (1).

Results: The analysis of the data gathered led to the establishment of the main theme "It's my responsibility". The main theme came as a result of a comprehensive understanding of eight different categories that were summarized and reflected upon by the author and two senior researchers. The categories were labeled as *knowledge about the disease, financial constraints, personal care, inappropriate behavior, safety of the PwD, psychological distress, positive aspects,* and *coping.* These categories allow understanding the pathway followed by caregivers while fulfilling their caregiving role, describing the challenges, positive aspects and coping strategies developed by caregivers. This works also unravels the needs stated by caregivers and possible areas for intervention by the government, health policy makers and health care professionals.

Conclusion: The experience of providing care for a PwD is vast and associated with a constellation of challenges that are deepened by social factors and welfare constraints in a low-income setting. Still, the experience of caregiving for a PwD also enables for positive experiences and the development of problem and emotion-focused coping strategies. However, more studies are required to better understand the experience of caregiving in low-income settings such as Uganda.

Keywords: *Experience, Coping, Caregiver, Dementia, Uganda*

CHAPTER ONE: INTRODUCTION

1.1 BACKGROUND

The World Health Organization (WHO) defines dementia as a syndrome in which there is deterioration in memory, thinking, behavior and the ability to perform everyday activities (2). According to the Diagnostic Statistical Manual of Mental Disorders (3), Dementia, which is also referred to as Major Neurocognitive disorder, is characterized by:

i. Substantial decline in one or more cognitive domains. These cognitive domains include complex attention, executive function, learning and memory, perceptual-motor, social cognition, and language. This impairment should be a cause of concern to the individual or informant or clinician and documented by neuropsychological testing or clinical assessment.
ii. Interference in independence in everyday activities resulting from the cognitive decline.

There are various etiological subtypes of dementia, including dementia due to Alzheimer's disease, which is the commonest and contributing to about 60% of all cases; vascular dementia; Lewy Body dementia; dementia due to Parkinson's disease; frontotemporal dementia; dementia due to traumatic brain injury; neurocognitive deficits (NCD) due to HIV infection; substance/medication-induced dementia; dementia due to Huntington's disease; dementia due to prion disease; dementia due to another medical condition; dementia due to multiple etiologies and unspecified dementia (3).

The WHO estimates the current global prevalence of dementia to be 50 million and this number is expected to increase in the coming years, reaching 80 million in 2030 and 152 million in 2050 (2). The estimated proportion of the general population aged 60 years and above with dementia at a given time is set between 5% and 8%. The same organization reports that nearly 60% of people with dementia live in low- and middle-income countries. Considering an economic perspective, this was translated into an estimated worldwide cost of US$ 818 billion in 2015, which is equivalent to 1.1% of the world’s gross domestic product (2).

In Africa, more specifically, there is a paucity of information on dementia. A systematic review on the prevalence of dementia in the whole continent describes the challenges while estimating these numbers, since only 10 relevant articles on the topic were found in different research platforms considering the period after 1980 (4). The same study found a prevalence of dementia in adults above 50 years to be about 2.4% in the whole continent, with 2.76 million people living with the disease in 2010, from which 2.1 million live in the sub-Saharan Africa.

The experience of falling ill can many times be challenging not just to the person directly affected by the disease, but also to those involved in the process, for example, relatives, caregivers, and other people that live with the affected person. This can be especially challenging when the disease compromises the ability of the person to be responsible for his or her own personal care, basic and instrumental activities of daily living. This is observed, among other diseases, in cases of moderate to severe dementia (5).

The experience of the caregiver varies depending on the setting and the degree of cognitive decline presented by the person with dementia. Still, caregivers will most likely experience social restrictions, financial strain, and emotional distress (6). Smith et al (7) found the burden of the caregiver to be multidimensional and divided this burden into three areas: (1) direct impact of care giving, (2) uncertainty around the future and (3) frustration / embarrassment. This multitude can be specially challenging in a low-income context such as Uganda, where the financial strains can deepen the struggle of an already frugal community. Deeper frustration could also be linked to a developing context, once the person with dementia might display an inappropriate public behavior that might be even more problematic in a setting of a lower education background and limited information about the disease (8).

The costs of caring for an individual with dementia should not only be translated into monetary value, but also in terms of psychological health and burden of the caregivers as well as the person suffering from dementia. A recent cross-sectional study estimated that, among the caregivers of patients with dementia, 62.2% were diagnosed with common mental disorder, 50% exhibited anxiety symptoms, 52.2% had depression symptoms and 66.7% reported burden (9).

Many different aspects can impact on the burden of caring for a person with dementia. Park and colleagues found that socioeconomic deprivation was associated with a larger increase in burden at a two-year follow-up study (10). Liu and colleagues found the burden to be dependent on the type of dementia, with a greater burden among caregivers of people affected by frontotemporal lobar degeneration and Lewy body dementia when compared to those affected by Alzheimer’s disease (11). However, Yan et al. found that the type of dementia had no impact on the caregiving burden. Additionally, the authors noted that a significantly higher burden was associated with being a female spouse or a sole caregiver. The study also stated that the type of primary care, frequency of care and need of help for key activities play a major role in terms of burden of the caregiver (12).

The importance of understanding the experience of the caregivers might have an impact into the care provided to the person with dementia. Decreased caregiving burden and increased caregiver satisfaction can contribute to the caregiver’s health and delay the institutionalization of the person with dementia (13) and this is a major motivation for undertaking this study, especially in a low income context.

1.2 PROBLEM STATEMENT

There is limited information about the quality of life and mental health of caregivers of individuals living with dementia in Uganda. Ndyanabangi and colleagues (14) describe that, specifically in Uganda, both family and patients of mental health conditions experience stigmatization, which includes cultural and social discrimination and family isolation, leading to the isolation and hiding of those affected by the disease. According to the same authors, elders with dementia are usually looked after by a fellow aged person, a female family member or, in some cases, a young child, and usually the family does not receive the necessary information regarding care and rights.

Taking care of a vulnerable person with dementia, along with the comorbidities, might represent an extra challenge in the context of a low-income country, where the health system might be weak to address and provide care for all the necessary levels. Additionally, the country might not have the resources required to provide a suitable welfare with, for example, financial aid to caregivers or access to free medication. Studying caregiver experience with a patient with dementia becomes an important field of study in such a context.

1.3 JUSTIFICATION/ RATIONALE

There is need for more information regarding the ways in which caregivers manage the caregiving experience with less strain and thus maintain or improve their quality of life (QoL) (15). This is especially true in a setting of a low-income country such as Uganda, where the caregiver burden may be exacerbated by social conditions and limited resource (poverty). This project aims to address the knowledge gap and help provide more information about the experience of caregiving in a low-income setting, so that the needs of the caregivers can be understood and adequate support and training can be provided in future programing by social service agencies in the country. This is quite important due to the increasing burden of mental disorders in Africa in general and Uganda in particular and the need for adequate policies, programs and legislations is getting more recognized.

Understanding the experience of caregivers of a person with dementia (PwD) will enable us to better understand the bottlenecks related to the care and the areas where a possible health policy and health support intervention could take place. We also aim to understand the variables related to the burden of caregiving and coping strategies, thus providing health workers with a better understanding on how to promote a more effective support to affected families.

1.4 RESEARCH QUESTION

Even though it is widely known that caregivers of a PwD experience an increased burden and decreased quality of life, there is still a knowledge gap regarding the description of the main obstacles found by the care providers, along with possible positive experiences and coping strategies adopted by the CGs. The information is even more limited in a low-income context, and almost none targeting the cultural context(s) found in Uganda. Therefore, this study explores the experience of caregivers as they provide care for a person with dementia (PwD) attending the outpatient facility at Butabika Hospital, Uganda.

1.5 OBJECTIVES

1.5.1 General Objective

To understand the experience of caregiving for a person with dementia (PwD) that attends the outpatient facility at Butabika Hospital, Uganda.

1.5.2. Specific Objectives

1) To explore the caregiver experience in caring for a PwD attending Butabika Hospital, Uganda.
2) To understand the obstacles related to care, as well as the possible positive aspects related to caregiving
3) To explore the needs and demands of caregivers when providing care for an individual with dementia on a daily basis.
4) To understand the coping strategies and support network used by the caregivers while providing care.

1.6 THEORETICAL FRAMEWORK

The conceptualization of the experience of caregiving for a PwD is commonly based on various stress coping models including the Lazarus and Folkman's transactional stress and coping model (16), which is summarized in Figure 1. According to this model, stress plays an important role in the care providing and care receiving relationship (17). The basic principles of stress coping models presume that beyond the care demands of patients with dementia, caregivers' physical and mental health are affected by their appraisal of caregiving situations and the availability of coping resources. The stressors described in Figure 1 as internal and external demands include primarily the level of cognitive impairment, frequency of problem behaviors, e.g. agitation, restlessness, wandering and aggression; the number of hours per day spent taking care of the patient and helping navigate through the health care system. A second set of stressors is due to the decline in the relationship between the care provider and care-recipient. Applying stress coping models to caregivers has shown that behavioral and psychological problems of a PwD are a common stressor for caregivers from diverse cultural groups (18).

The model proposed by Lazarus and Folkman (16) states that stress is the product of a transaction between an individual and his or her complex environment. This model posits that situations or experiences are not inherently stressful but are experienced as stressful following a two-stage appraisal process by the individual, represented in Figure 1 by the arrows coming from “appraisals”.

The first step, shown by the arrow in the left (Figure 1), is called the primary appraisal. In this stage, an individual determines if a given situation is stressful or not. This is greatly influenced by *personal attributes*, such as the personality and past experiences, and by *stable environmental attributes*, like culture and background. Secondary appraisals (arrow to the right), on the other hand, concerns deciding whether an individual can manage the stress and selection of a coping strategy to deal with the perceived threat. This secondary process is more situation-dependent than the initial appraisal and is generally the target of interventions (19).

Coping strategies have been traditionally conceptualized into two major categories: *problem-focused coping* and *emotion-focused coping categories*, defined by Lazarus and Folkman (16) as minimizing emotional distress caused by one’s interaction with the environment. Problem-focused coping styles were defined as those methods in which individuals take action to change the relationship between themselves and their environment and to change the individuals’ relationship to the stressor (16). *Emotion-focused coping* styles involved reducing the level of perceived emotional distress caused by the stressor and might be effective when individuals think they cannot avoid the source of stress. Emotion-focused strategies are notably diverse and heterogeneous in nature; traditional examples include wishful thinking, avoidance, counting blessings and more recently described in the literature, spirituality, and forgiveness. Individual coping strategies have been identified as moderators of the caregiver’s mental health and emotional outcomes. *Problem-focused and direction-action related coping* have generally been associated with caregiver well-being and positive outcomes, including more satisfaction in the caregiving role (19). Emotion-based coping, on the other hand, has been associated with depression and negative psychological outcomes for the coping individual (20).

Following this stress coping model described in Figure 1, the coping strategies will lead to short- and long-term outcomes, with the former having an impact on the latter. The ability to relax and the mood changes experienced by caregivers (CGs) in a first moment will influence their physical and mental health, which might finally have an impact on life satisfaction.

Drawing on the stress coping model from Lazarus and Folkman, this study defines stress as caregiver appraised difficulties that could cause feelings of frustration, anxiety, or uneasiness, while coping is considered as a process that involves cognitive and behavioral approaches to deal with distressful situations. In line with such considerations, this study posits that stress and coping comprise the cornerstone of the dementia caregiving experience.

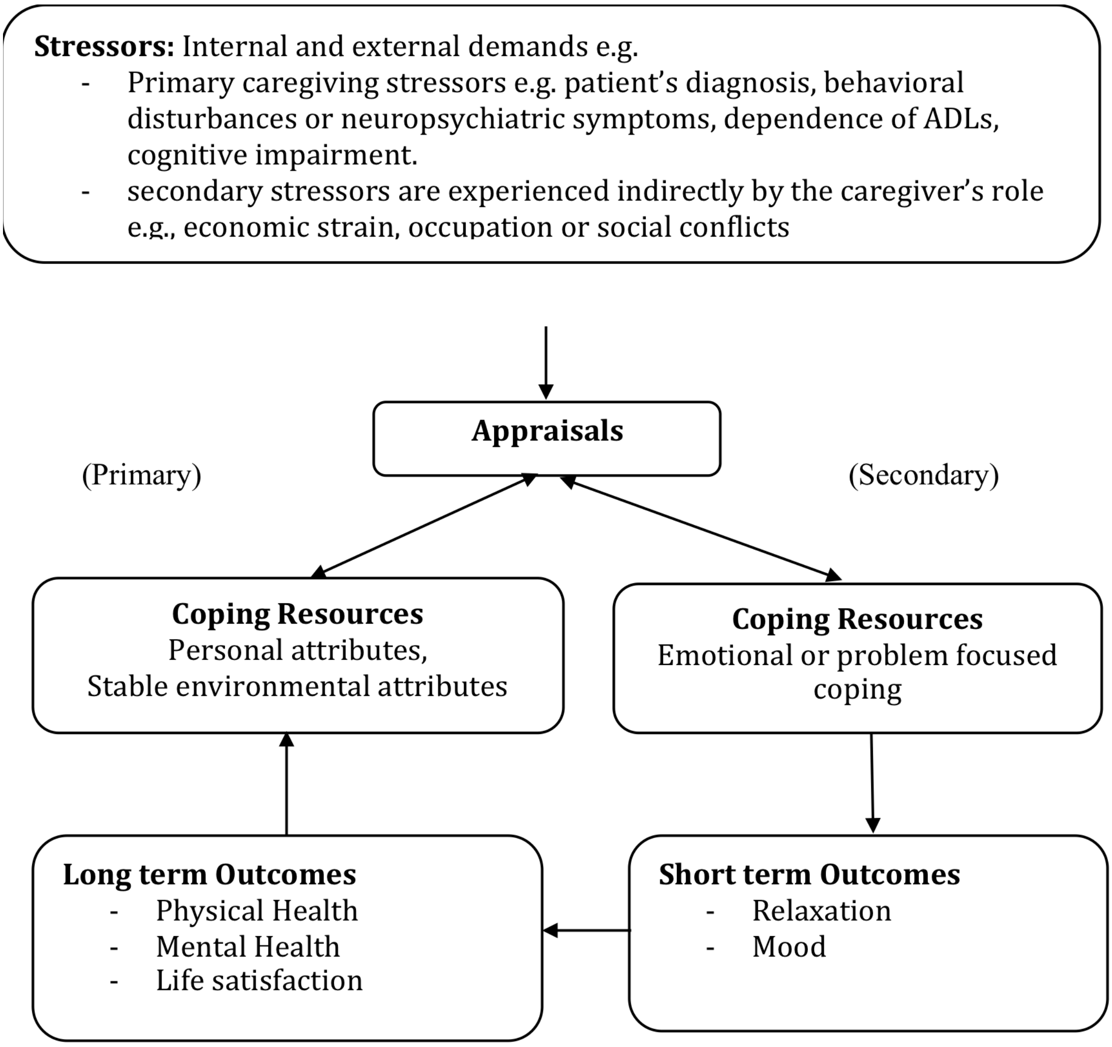

Figure 1: Stress-coping model (21). Copyright © 1984 by Springer Publishing Company, Inc. 11 West 42nd Street New York, NY 10036-8002

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

Mental health is a state of complete happiness, which refers to the ability to enjoy life and cope with challenges (22). It is also related to the concept of quality of life (QoL), which is defined by the World Health Organization as "Individuals perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, standards and concerns" (23). QoL is a broad ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment. This definition highlights the view that QoL is subjective, includes both positive and negative facets of life and is multidimensional (23). Every and each facet of QoL is essential for a caregiver to be able to provide care for an individual with dementia. Caregiving for any individual places a lot of responsibilities and strain on the caregiver. This is more so when in addition to caring for the individual singlehandedly, the caregiver has other duties either within or away from home. These role conflicts and the emotional demands of giving care increase the burden on caregivers.

2.2 CAREGIVING IN DEMENTIA

Over the past years, there has been a substantial growth in the older adult population (24). Older adults are now living much longer with advanced stages of age-related comorbidities, such as cognitive impairment. Worldwide, around 50 million people have dementia and the global incidence of dementia is approximately 10 million new cases each year (2). Some people with memory problems may be living without a formal diagnosis or may avoid visiting their general practitioner (GP) through fear and stigma of the disease (25). As the disease progresses, there is an increase in the dependency of the PwD to receive care from another person, identified as CG.

The Alzheimer's Disease International (ADI) estimates that, globally, approximately 84% of elderly patients with dementia live at home and are cared for by nonprofessional family caregivers (26). Nonprofessional caregivers (NCs) assume responsibility for providing care in a nonprofessional, unpaid manner, based on family or affective ties (27). People with dementia are often cared for by people with whom they have a preexisting relationship, particularly spouses or adult children (28). Caregivers in developing countries spend, on average, 3 to 6 hours a day with the person with dementia, and 3 to 9 hours assisting with activities of daily living. Eleven percent to 25% of caregivers spend more than 11 hours per week providing informal additional support (29). As people are more likely to live in large households, care is distributed among a greater number of individuals, and there is some evidence that the main caregiver experiences less strain (30).

However, because of lack of knowledge and understanding of dementia, NCs do not understand why these older individuals behave as they do or what the future may hold for them. In recent years, multiple studies have shown that, in caregivers of a PwD, poor mental health is widespread, with anxiety and depression being the most common symptoms, reported by more than 50% of caregivers (31) .

2.3 EXPERIENCE OF CAREGIVERS OF INDIVIDUALS WITH DEMENTIA

Providing care for an individual with dementia may prove to be extremely stressful and has far-reaching consequences. Because dementia involves progressive cognitive decline, caregivers must manage changing demands and unexpected problem behaviors. Caregivers help with a variety of activities of daily living (ADL) including mobility, self-care, and communication and other personal and household activities, such as health care, cognitive tasks, and various household chores. Caregivers often sacrifice their own needs and wellbeing to provide care for their loved one. The distress experienced by caregivers is typically referred to as caregiver burden, which includes both objective aspects of providing care (e.g., time and physical aspects of providing caregiver) and subjective experience of caregiving (e.g., perceptions and emotional reactions to caregiving) (32). Those caring for a PwD usually experience greater burden (33). The burden of the caregiver is directly related to the QoL of the PwD. QoL ratings by the person with dementia have been associated with high caregiver stress, high perceived social restrictions and low care giving competence (34). On the other hand, there are also positive aspects of caregiving for a PwD, such as the activity being perceived as meaningful and as a source of satisfaction (35).

2.3.1 Negative Aspects of Caregiving in Dementia

Mental Health consequences of Dementia Caregiving

Dementia caregiving is associated with a variety of negative mental health consequences. Caregivers of a PwD were reported to have higher levels of depression, emotional distress, and physical strain than caregivers of older adults with physical impairments (26,36). Caregivers of a PwD report high levels of depression and anxiety and exhibit elevated rates of mood disorders, with about 1/3 of individuals meeting diagnostic criteria for depression (37). A qualitative study conducted with partners of elders with dementia in Mexico described their caregiving experience as "tiring," "wearing," or "hard." Those partners reported suffering from stress, insomnia, nervousness, migraines, and/or depression because of their care giving experiences (38).

Subjective caregiver burden is a significant risk factor for depressive symptoms in CGs of older people and may precipitate clinical depression. Other factors associated with depressive symptoms in caregivers include older age, behavior problems presented by the PwD, more severe cognitive and functional impairment, more hours providing care, greater number of caregiving tasks and longer duration of caregiving, subjective health status, economic activity, monthly mean household income, female caregiver, spousal caregiver and less social support (15,36,39,40).

Owing to the severity of this mental health situation, recent research also suggests that caregivers may be a high-risk group for suicide (41). One study found that over the course of two years, a number of people caring for a relative with dementia repeatedly considered hurting themselves, felt suicidal, or wished they were dead (42).

Physical Health Consequences of Dementia Caregiving

Providing care for an individual with dementia can also lead to increased risk for physical health problems, both in terms of perceived health and more objective health measures (17,36). Caregivers report a greater number of physical health problems and worse overall health compared to non-caregiver controls (43). Some theories have been put in place to explain this association. It has been proposed that the chronic stress associated with caregiving may negatively impact the immunologic and hormonal functioning, thereby increasing susceptibility to illness. Furthermore, there is evidence that CGs of a PwD neglect their own health, such as not getting enough sleep, having poor nutrition and decreased engagement in preventative health behaviors, such as exercise, which places them at higher risk for illness (17).

Predictors of poor health among CGs include behavior problems and cognitive impairment in the care recipient, longer duration of caregiving, low socioeconomic status and education, female caregiver, limited social support, older age, co-residence with the care recipient and high levels of depression/burden (44).

There have been several findings related to the health of caregivers, including death and development of their own cognitive impairment. Schulz and Beach showed that caregiving was an independent risk factor for mortality, with caregivers experiencing a 63% increased risk of death over 4 years compared to non-caregivers (45). Similarly, spousal caregivers of individuals with dementia had a higher mortality rate after hospitalization of their spouse than spousal caregivers of individuals hospitalized for reasons not related to dementia (46). Epidemiological data has also showed a six-fold increased risk of dementia in spousal CGs compared to non-caregivers (47).

Social Isolation

Caregivers often lack social contact and support and experience feelings of social isolation (48). Caregivers tend to sacrifice their leisure pursuits and hobbies, to restrict time with friends and family and to give up or reduce employment (48,49). Caregivers who are more satisfied with their social interactions show fewer negative psychological symptoms (50).

2.3.2 Positive Aspects of Caregiving in Dementia

Although the focus has been predominately on the negative consequences of caregiving for a PwD, there is a growing literature on positive aspects of providing care. Not all caregivers experience distress and burden, especially very early in the caregiving process (51). In addition, there is evidence that the length of caregiving may result in instability or decrease in burden and may increase the time to nursing home placement, suggesting adaptation to the caregiving role (52). Most caregivers report some degree of satisfaction while providing care, including feeling needed and useful, feeling good about oneself, learning new skills, developing a positive attitude and appreciation for life, and strengthening relationships with others (35). Positive aspects of caregiving are inversely related to burden and depression and have the potential to buffer against the negative consequences. Caregiver personality characteristics such as extroversion and agreeableness along with social support (especially from one’s spouse/partner) are associated with higher reports of positive aspects of caregiving (53).

CHAPTER THREE: METHODS

3.1 PRE-UNDERSTANDING

It is widely accepted that the researcher plays an important role in qualitative research (54), and that the interpretation of data free from presuppositions is impossible to reach (55).

According to Gadamer (56), the pre-understanding is a structure that is activated when a person is regarding something *as* something. Therefore, the pre-understanding emerges as a result of the tradition and context with which the researcher is familiar. In this context, understanding the data is based on the historically accumulated structure by the researcher (56). This structure might work facilitating or hindering the understanding of the data. Hence, interpretation emanates from a certain horizon or point of view (57).

Particularly in this study, the main investigator is a female Brazilian psychiatrist with many years of experience in the field of Geriatric Psychiatry. Based on her experience handling patients with dementia and their CGs, the author expected a scenario similar to the one in Brazil, considering the developing profile. Based on her previous experience, the author expected to interview primarily female caregivers, believing that the caregiving role would be taken mainly by female CGs. The author also expected to find the main challenges focused on hygiene and day to day care by CGs. The investigator was aware of the economic and developmental struggles in Uganda and was therefore curious about where the coping strategies would arise from. She believed that the needs of CGs would be restricted to demanding better economic inducements for caregiving. The author was concerned that the fact of being a female, foreigner and educated interviewer could inhibit interviewees.

As for the epistemological approach, the researcher adopts a Constructivist paradigm, assuming that there is no single reality, but that she elicits participants' views of reality while conducting the interviews and analyzing the data (58). As a result, there can be no '*absolutely right interpretation*', as right in itself is an impossible and thoughtless ideal (56).

To ensure the rigor and trustworthiness of this study, the researcher analyses the degree of influence that she exerts, either intentionally or unintentionally, on the findings. This reflexivity contributes to the awareness of one's own bias, and will be explored under the last section, “Discussion”, along with the resources enacted by the researcher to ensure validity of the findings, such as peer examination of the analysis by two other senior researchers.

3.2 STUDY DESIGN

This was a qualitative descriptive study, based on in-depth semi-structured interviews with open-ended questions in line with Kvale and Brinkmann (59). The choice for a qualitative design is based on its ability to explain processes and patterns of human behavior that can be difficult to quantify. Additionally, a qualitative design can allow for a broader understanding of topics where the current literature available is meager (60). In this context, a qualitative approach allows participants themselves to explain how, why, or what they were thinking, feeling, and experiencing in the course of care giving for a PwD (61).

3.3 STUDY SITE

This study was conducted at Butabika National Referral and Teaching hospital. Butabika Hospital is located about 10 km East of Kampala City and it is the second biggest hospital in Uganda, with a bed capacity of 550. Butabika Hospital was established in 1955, and it is the only specialized Mental Health Institution in Uganda. In addition to the provision of mental health services, Butabika hospital is also a teaching center to various professionals undertaking mental health as part of their course. The participants for this study were recruited from the outpatient department as most of the individuals with dementia are managed on an outpatient basis. This department runs seven days per week, receives about 50 to 70 patients per weekday and about 20 to 30 patients on the weekends. From the patients seen per day, two to five patients have dementia. Psychiatric clinical officers, medical officers, senior house officers and psychiatrists manage the patients in this department.

3.4 SAMPLING PROCEDURE

A number of 15 caregivers were recruited from Butabika Hospital using purposive sampling (62). Even though there is no consensus regarding the initial number of participants that should ideally be recruited in a qualitative study (63), Kvale *et al* suggest 15 as a suitable starting point (59).

Participants were identified through the screening of the patients' journals. All the information regarding the patients were kept at the hospital Medical Records Units and hard copies were analyzed by the hospital's staff from Jan 20th 2021 to Feb 2nd 2021 in search for those patients with a diagnose of Dementia, along with their phone contact and information about the caregiver. During this period, a total of 21 caregivers were identified. Once a caregiver was identified, another member of the staff would contact the prospective participant in Luganda to explain about the research and invite for participation. From the 21 identified participants, 15 agreed on taking part in the study. From the 6 remaining that were not included, 3 moved to a district over 100 km away from Kampala, 1 was sick and 2 were unreachable after multiple phone call attempts. The sampling procedure is summarized in Figure 2.

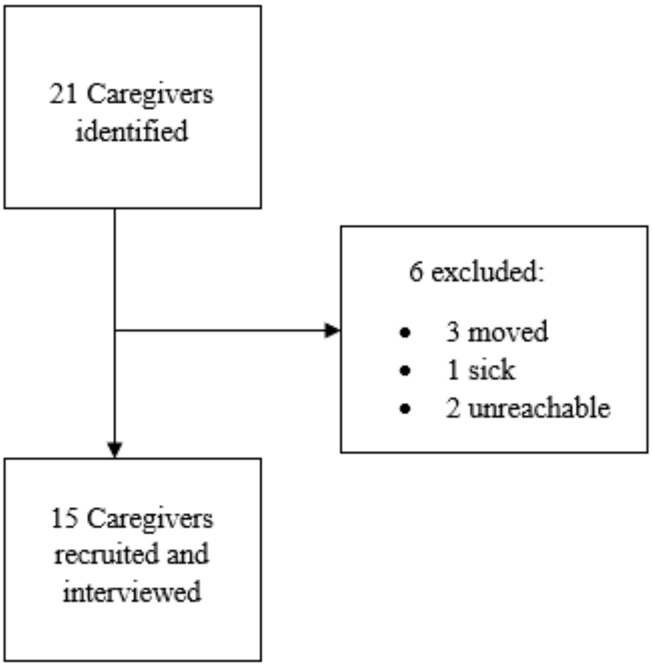

Fig.2 – Summary of sampling procedure

Fifteen participants fulfilled the inclusion criteria and were recruited to be interviewed either at Butabika Hospital or at their own home, depending on the participants' choice. The inclusion criteria were: (1) the caregiver selected was a person with a close family relationship or the person who was directly responsible for the care. (2) The CG had to be living with the patient for at least six months. A shorter period was considered in cases where the start of symptoms was shorter than 6 months. In that case, the participant was required to be the one responsible for care since the start of the symptoms. (3) Only adult caregivers were recruited into the study (age > 18 years), and (4) only those who could attend an interview. Therefore, the inclusion criterion was also limited to (5) participants living within 50 km from Kampala. (6) We only included those who gave consent to participate in the study. (7) Those that could not speak English or Luganda were excluded, as these are the languages that were used for the interviews. The language choice was based on the fact that English is the official language of Uganda and Luganda is the most widely spoken local language, given that the Baganda tribe is the most dominant group in Kampala region (64), where the study was conducted.

The interviews occurred from Jan 21st 2021 to Feb 4th 2021, with 13 of them taking place at the hospital environment and 2 in the informant's home. The ones visited at home were still within the hospital catchment area. From the 21 identified CGs, 11 were men and 10 women. During the recruitment process, 1 woman and 5 men were excluded. From the recruited participants, six were men and nine women, with age varying from 23 to 70 years. Table 1 presents the participants (anonymized) and their characteristics.

Table 1. Characteristics of the participants.

Identification	CG Sex	CG Age	Relation to patient	Patient Sex	Patient Age
P1	M	36	Nephew	M	97
P2	F	23	Daughter	M	56
P3	F	38	Daughter	F	71
P4	F	53	Wife	M	61
P5	F	43	Niece	F	69
P6	M	45	Son	F	67
P7	M	33	Son	M	54
P8	M	53	Son	F	79
P9	F	70	Daughter	F	90
P10	F	43	Daughter	F	80
P11	M	40	Son	F	82
P12	F	40	Daughter	F	70
P13	F	52	Sister	F	75
P14	F	51	Wife	M	68
P15	M	23	Professional CG	M	65

Note: M = male, F = female, CG = caregiver.

3.5 STUDY TOOLS

Data collection was based on in-depth, semi-structured interviews, which are deemed important in collecting rich data on individuals' lived experiences. To guide the interviews, the researcher established a semi-structured interview guide with open-ended questions in line with Kvale and Brinkmann (59). Using a semi-structured guide allowed the interviewer to pursue topics that emerged during the interview (65) that seemed relevant to the proposed study. The guide is attached in the appendix (Appendix III and IV)

3.6 STUDY PROCEDURE

Caregivers fulfilling the inclusion criteria and willing to participate were invited to meet at an agreed convenient location either at the hospital or at home. Thirteen interviews were held at the hospital environment and two at the participants' home. Due to the Covid-19 pandemic, all standard operating procedures (SOPs) were observed in both settings, with social distancing of at least 2 meters from the participants, the use of face masks and alcohol 70% available always. The research was explained again and written informed consent obtained, both in English and Luganda. The interview was conducted in English by the masters student. In cases where the participant was not fluent or comfortable with using English, a translator was also present during the interview to perform the translation English-Luganda-English, in order to make the interviewees more comfortable and able to express her or his ideas more clearly. The translator was an experienced mental health professional (with over 8 years in the field), who was born in the same ethnic group as the study participants and fluent in both Luganda and English. The simultaneous translation during the interview also allowed for new topics to be explored and clarified as they rose from the interviewees' speech. To adjust for cultural idiosyncrasies, the interviewer used techniques such as asking clarification questions or asking for examples to better illustrate the topic under discussion (59).

In the cases were participants got emotional during the interview, they were given room and time to express these emotions and appropriate counseling was offered by the hospital staff.

3.7 DATA PROCESSING AND ANALYSIS

The average duration for the interviews was 54 min. Interviews were recorded using a Sony ICD-PX370 voice recorder, and were anonymized. For those interviews conducted solely in English (four out of fifteen), the interviewer herself transcribed *verbatim* the content. Interviews that were conducted both in English and Luganda (eleven interviews) were translated and transcribed *verbatim* by a second mental health professional who is also a psychologist, but different from the one present during the interviews. The involvement of a second person in the translation process, besides the first translator, was a decision that was thought through in order to increase the reliability of the data gathered, since the literature advises for the use of at least two different translators to ensure data quality (66,67). In this case, the interviews were subject to two different translations from Luganda to English by two mental health professionals. The first translation was a real time work during the interview, helping to accomplish a dynamic interview with the possibility of exploring new topics that were brought by the interviewees and assuring cultural and semantic understanding. The second translation was made by another mental health professional and was based on the recorded interviews. Following this procedure, the second professional translated and transcribed the interviews from Luganda to English, so that the data can be based not on paraphrases, but in real content translated directly.

The information gathered was then analyzed according to qualitative content analysis inspired by Graneheim and Lundman (1). To conduct the analysis, the researcher managed the data by using the software Nvivo 1.3. The included caregivers could be approached if the researchers needed clarification while analyzing the content of the interviews. While doing the finals analysis, the theme and categories that emerged in the data were agreed upon by the researcher and both the academic supervisors

The interviews were read through several times to obtain a sense of the whole and considered as a *unit of analysis*. These units were then scrutinized line by line to identify the *meaning units*, that were condensed into descriptions close to the text and identified as *condensed meaning units*. The condensed meaning units were abstracted and labeled with a *code*. The codes generated in the previous process were compared across all the interviews based on differences and similarities and sorted into *sub-categories*. These sub-categories were then clustered into *categories*, which constitute the manifest content of the data and arrange based on each specific objective that guided the study. Finally, the categories led to the formulation of the main *theme*, "it's my responsibility", considered to represent the latent content of the underlying meaning of the categories (1,68). This process is exemplified in Table 2, whereas Table 3 displays the development of the main theme, the categories, and sub-categories. A complete dataset including the codes used to generate the sub-categories is available as Appendix V.

Table 2. Example of data division and classification.

Meaning unit	**Condensed Meaning Unit**	**Code**
"she got lost and we spent the whole week looking for her [PwD]. *I fear that she might get lost" (P10)*	Fear for the patient to get lost	Fear for the safety of the patient

Table 3. Example of data division and classification based on the theme, categories and sub-categories.

Theme	Categories	Sub-categories
It's my responsibility	Knowledge about the disease	Causes of the disease
		Alternative search for help
		Information regarding the disease
		Need for alternative sources of Information
		Stigma
	Financial constraints	Decrease in the household income
		Increase in the expenses
	Personal care	Feeding
		Hygiene care
		Excreta
	Inappropriate Behavior	Violence
		Incivility
		Damaging and losing items
	Safety of the PwD	Concern for the patient to get lost or run away
		Concern for the patient's integrity
		Concern for others taking advantage of the PwD
	Psychological distress	Sense of being overwhelmed
		Lack of Sharing the Care
		Sleep disturbance
		Appetite changes
	Positive aspects	Sense of control
		Blessings
		Improving means
		Maturity
		Social Bounds
		Insights
	Coping	Family Support
		Friend's support
		Community support
		Health care support
		Faith
		Sense of Duty
		Hope for improvement
		Sense that other people also endure caregiving
		Learning how to care

3.8 ETHICAL CONSIDERATIONS

This project was approved by both to the School of Medicine Research and Ethics Committee and the Regional Committee for Medical and Health Research Ethics in Mid-Norway. Permission was also obtained from the Research Ethics Committee board from Makerere University in Uganda, along with the administration of Butabika Hospital and the in-charge of the outpatient department. Written informed consent was obtained from all the participants. To foster informed consent, the informants were provided full information about the study, especially its objectives, benefits and were assured that there were no risks associated with the study that were known to the researchers.

The participants were presented a written information sheet and an informed consent form (Appendix I and II) by the Master student, Lílian Mayerhofer, and the respective translator. For those who cannot read or write, the information was read to them in presence of a literate witness, preferably selected by the participant and with no connection to the research team after which they consented by thumbprint. All participants were assured of confidentiality and their information anonymized, and no sensitive information was gathered. To ensure more confidentiality, data were encrypted with the use of a symmetric-key algorithm – Advanced Encryption System (AES) and the key was only accessible to the research team.

As part of the information sheet, the researchers provided the participants with an e-mail address and telephone number, where the researcher and translator were available to answer any further question. Participants were assured that they are free to withdraw from at any stage of the interview without reprimand. An informed voluntarily statement of consent was collected by the translator. The consent forms and the transcribed data were kept under cryptography for digital data and key and lock for the hard copies for three years after the completion of this study and only the researchers will have access to the data. After three years the transcriptions, the consent statements and the records will be disposed.

3.9 CONFLICT OF INTERESTS

There is no conflict of interest among the researchers involved in this study.

CHAPTER FOUR: RESULTS

4. RESULTS

The analysis of the data led to a comprehensive understanding of the experience of caring for a PwD attending Butabika Hospital. This experience starts even before the establishment of a formal diagnose of dementia, with the CG's attempts to find a meaning and give an explanation to the symptoms, based on their previous experience and cultural beliefs. This is described under the category "*knowledge about the disease*", which also includes the journey through alternative solutions portrayed by CGs until reaching the health care system.

When describing their caregiving experience, CGs indicate a constellation of hardships faced in the daily care and in a more macro perspective. These challenges where clustered into the categories (1) *financial constraints*, (2) *personal care,* (3) *inappropriate behavior*, (4) *safety of the PwD* and (5) *psychological distress.* These same five categories, along with the first one regarding the knowledge about the disease, also allow for the understanding of the needs and demands of CGs, posing possible intervention gaps that could be addressed by the health care system and policy makers.

To have a whole sense of the experience of caregiving, the author also explores the possible positive experience encountered by CGs in the course of caregiving. This is described under the category "*positive aspects*".

Finally, under the objective "to understand the coping strategies and support network used by the caregivers while providing care", the category "*coping*" emerged. This category explains coping and networking through the establishment of nine sub-categories, (1) family support, (2) friend's support, (3) community support, (4) health care support, (5) faith, (6) sense of duty, (7) hope for improvement, (8) sense that other people also endure caregiving and (9) learning how to care.

These categories led to the establishment of the main theme "It's my responsibility". This theme came resulting from a comprehensive understanding of the eight different categories mentioned previously, that were summarized and reflected upon by the author. The categories, as well as the theme and the subcategories, will be further explored in this section. To better exemplify each topic, the author uses quotations extracted from the interviews. In cases where the same topic is described in different moments of the interview, the author uses the notation […] to link the speech and express that there was a change of topic in between. Therefore, the notation […] denotes that the part of the speech that was not directly related to the topic was dismissed and that quotations that were align within the same topic, but not stated one right after the other by the interviewee, could be assembled to exemplify the results of this study. Additionally, the notation […] was used based on ethical principals and as means to preserve the integrity of informants, suppressing parts that could compromise participants' anonymization or parts that were requested by participants not to be published.

4.1 KNOWLEDGE ABOUT THE DISEASE

This category is composed by the knowledge offered to the CG about the disease, as well as the outcome of a possible lack of information by the community, leading to stigma towards the CG and the PwD. By knowledge about the disease, this category also includes cultural information regarding what is believed to be the possible causes of the disease, and the imminent need for more information about care providing and the underlying condition of the PwD.

4.1.1 Causes of the disease

While some participants stated they didn't know the cause of the disease, others described an array of possible causes to the disease presented by the PwD, ranging from a normal process of aging to accidents, lifestyle, and witchcraft. In four cases, participants established a clear link between the disease and an accident involving the PwD, more commonly a traffic accident with a motorcycle, considered to be one of the most common transportation used in Uganda:

"she [PwD] *was so ok and healthy and she used to cook her own food very well and she even used to go to the garden. Now that accident with the bodaboda* [motorcycle] *that knocked her is what brought problems" (P9)*

In some other cases, the source of the disease was linked to aging and the lifestyle perpetrated by the PwD. Lack of leisure time activities, overworking, eating habits and loneliness were described by participants as possible sources for the illness to strike:

"she [wife] *has so many things that she gave him* [PwD] *to eat and the brain got spoiled completely" (P1)*

"she [PwD] *used to stay alone because my brother, he is married, so she used to stay in the house alone. So, I think given that she was staying in the house alone, maybe she got a problem maybe of depression, maybe the situation was caused by that" (P10)*

"maybe it's because she [PwD] *used to overwork. She never got time to sit at home, relax. No. She would never go out" (P3)*

Lastly, culture and religion are also considered by CGs as possible explanations for the disease of the PwD. In this case, the PwD is believed to develop the disease as a punishment for a heretic action, such as voluntarily damaging sacred items belonging to the traditional cults:

"Now when she [PwD] *burnt them* [traditional items]*, the clan elders called her children and told them that their mother had burnt the clan's traditional witchcraft things, so something bad will happen to her. [...], so, for us we think that those evil spirits that she burnt without having the energy to fight them* [caused the disease]*." (P5)*

Along with the religion beliefs, some CGs posed that the PwD became ill resulting from being harmed by other people with the use of witchcraft:

"the co-wives bewitched her [PwD]*" (P13)*

4.1.2 Alternative search for help

Along with the different causes believed to be the source of the disease, comes the alternative search for help, which is compatible with the attributable cause of the disease. This alternative search for help comes prior to seeking treatment at the health care system. The alternatives include taking the PwD to Christian churches, to Muslim leaders and to authorities in the local religions, as well as also counting on witchcraft:

"we tried in those sheikhs that say prayers and we went to churches and also traditional healers" (P2)

"So, I thought that if I go before God and tell him to forgive her [PwD], [...], heal her, so when I brought her, we went to church" (P5)

"they [sisters] *took her* [PwD] *to the witch doctors" (P5)*

"So, we first went to traditionalists until we got misunderstandings in the family, some of us wanted that we go to the hospital and others wanted to go to traditionalist" (P13)

"we tried the traditional healers and even taking her [PwD] *to Pentecostal church to pray for her" (P13)*

The endeavor through the different sources of possible solutions had brought along a delay in searching for help within the health care system:

"We spent two years when we were in those things of praying for her [PwD], *traditional things, and even one thing was bringing in witchcraft" (P13)*

4.1.3 Information regarding the disease

Before becoming a CG, participants indicated they had no previous knowledge about dementia. According to the narratives, participants didn't have any previous contact with a PwD. There are some mentions of seeing other elders in the past with similar symptoms, but without a well-established diagnosis that was known by the participants:

"There was this neighbor close to where you passed...I think she is like my mother [PwD]*" (P9)*

“I had never seen this type of diseased” (P4)

“Because we did not know so much about it. We have never seen it” (P3)

By the time the PwD receives a diagnose and starts the treatment within the health care system, some CGs expressed that they were given information about the disease and what is expected regarding the progression of the symptoms and the proposed treatment:

“we were contented [with the provided information] *because the doctor spent on us very many hours the first time that I brought her* [PwD] *to [the hospital]” (P11)*

Other CGs, however, claim they were not provided with enough information about the disease, especially regarding how to care for a PwD, what new challenges to expect and how to tackle them:

“I have not got enough [information about the disease]*” (P6)*

In some cases, the PwD had a regular follow-up at the hospital and was already on medications. Still, CGs argue that no guidance was provided in caregiving, other than medication. CGs leave then the doctor’s office with a prescription, but still hold a feeling that they didn’t have all their questions answered. This lack of information gives place to a feeling of not being a part of the treatment and the care process:

“they [health workers] *have not given me enough information because there are tests they told us to do and we did them, but he* [doctor] *looked at the tests and didn’t even explain to me that she* [PwD] *is sick, or that she is suffering from this or that. He just wrote down the medication and sent me to the pharmacy, but I wanted to know what really is disturbing my mother and I didn’t get it.” (P10)*

“the doctors tell you that you give her [PwD] *what to eat and to give her medicine, but they don’t have anything different more than that to offer.” (P9)*

4.1.4 Need for alternative sources of Information

Due to the information gap left by the health care system, CGs need to rely on other sources of information, like neighbors, friends, and the internet:

"I always get it [information about the disease] *from the internet. I read about it" (P3)*

Since there is no support group for CGs of a PwD known by the participants, and the access to the internet is limited, as well as reliable sources of information, CGs claim a need for a space where they could be advised on how to handle the care, get more information about the disease and the possible treatments and interventions, and could also exchange information with other CGs of a PwD:

"I would like to have a doctor or somebody who knows more about the disease, and he can help me to know how I can handle, how I can deal with this person [PwD]. Because right now I'm just guessing. I'm on guess work." (P3)

"I don't have any other person that I know who has a patient in a condition like this one, that we would give each other advice" (P9)

4.1.5 Stigma

Throughout care providing and treatment, along with the connection to the health care network, CGs get different degrees of information regarding dementia. Still, the same might not be true to the community where the PwD and the CG live. In this case, villagers might still attribute the disease to evil spirits or because of bad actions committed by the PwD. Therefore, some CGs claim to suffer stigma from the local community:

"the other challenge I got…people on the village going while talking about me. 'That one's father is mad', 'her father is mad'. […] *they say that he* [PwD] *is possessed, he is mad" (P2)*

"you know what I got tired of, like how you know village talks, they make him [PwD] *a topic so sometimes I can be there and just keep quiet." (P4)*

"Some people call him [PwD] *a mad man. The villagers say he is a mad man" (P7)*

Alternatively, other CGs didn't state stigma as a problem, but rather describe the villagers as supportive and understanding:

"There is not discrimination at all" (P5)

"the people in the area have no problem with me" (P9)

As seen from the voices above, our informants lacked appropriate information relating to dementia, such as the disease's etiology, course and treatment, and this had an impact in caregivers' experience. The lack of information by the community also affected informants, so that participants experienced stigma at some point during the care.

4.2 FINANCIAL CONSTRAINTS

Almost all the 15 participants experienced apprehension, concernment, and anxiety regarding the financial area because of caregiving. The only exception was Participant 15, since this case represents a professional caregiver hired by the patient's family to assist with the daily care. The financial concern was attributed both to a decrease in the family income and an increase in the expenses related to the treatment and care of the PwD, such as affording for medicines, transportation to the hospital and hygiene items.

4.2.1 Decrease in the household income

In most cases, the CGs described a decrease in the income resulting from a reduced working ability, with less hours spent at work or the need to completely cease working because of the time spent providing care. This was especially challenging for CGs bearing the double burden of caregiving and being financially responsible for providing for the family:

"I feared that she [PwD] *might get lost again and yet I have to also work and also look after the patient" (P10)*

"my job money is little, because now if you know you have been making 500.000 shillings, and now you are making 70.000 shillings. It treats you bad. The situation is not good." (P1)

"it has affected a lot my life because I cannot work. I no longer work. […] *it is related a lot to the situation he* [PwD] *is in right now because you cannot leave him at home and go out. The children who are there* [at home] *are young. You can't leave them with him because you have to look after him, cooking" (P2)*

"it [caregiving] *affected me a lot, a lot because where I was getting money, now I no longer work." (P10)*

"it has affected me because the time I could work, I don't work most times, because you leave and they [relatives] *call you to come home* […] *because she* [PwD] *is ill now. I have to be very near her* [PwD] *most times, I have to quit work to see if she is ill, I take her to hospital like that" (P6)*

In some narratives, the PwD played a central role in the household income in the period prior to the start of the symptoms. With the cognitive decline and loss of the ability to work, the family dynamics had to be reorganized in order to make the ends meet, with new financial providers arising and increasing the burden to those who were already financially responsible for the income:

"he [PwD] *used to buy some of the things at home and I also buy, but now it's me buying them alone" (P4)*

The degree of impairment in the working ability and profiting from business were also attributable to the impact of the current Covid-19 pandemic, where business were closed, the unemployment rate increased sharply and the Economy declined at a national level in Uganda (69):

"I had rentals. No, it's because of Covid. Tenants ran and went to the village and getting other people is hard" (P1)

"Covid 19. That is the problem. So, before the pandemic there were customers" (P1)

"I had a saloon but when they closed them in Covid, I failed to pay rent, now currently I'm not working." (P5)

"but I didn't have money because I was no longer working. From when Covid came, I was no longer working." (P14)

4.2.2 Increase in the expenses

Caregivers described a struggle affording the increase in expenses related to caregiving. The costs covered a wide range of necessary steps in the treatment of the PwD and care providing, accounting for medical exams (CT scans, MRIs, blood tests), commuting to the hospital, paying for private medical evaluation and treatment. In some cases, caregivers would also rely on items that would make the caring more bearable, like using disposable pampers on the PwD and wearing gloves while handling excreta. However, those were also implied in the increase of the expenses:

"I also have to look for money for the hospital" (P4)

"they [hospital] *have been taking a lot of money from us. I went to* [hospital] *where the brain machine was 350.000 shillings, and not only one scan, they had to take so many scans, so the situation didn't become easy to try and look for that money. But that's how the situation is, just hustling, but money for treatment is hard get" (P11)*

"my main challenge is that they [relatives] *don't have money.* […] *when I'm with her* [PwD]*, it is really expensive." (P5)*

"I don't have money and even where I used to get money, I no longer work. […] *Now the problem you might find is when the gloves are finished and when I don't have pampers" (P9)*

From all the expenses related to caregiving, the one CGs would highlight was the cost related to affording the medicines required for the treatment of the PwD. CGs found it was imperative to provide the PwD with the prescribed medicines, but many could not afford buying them at private pharmacies. In some cases, the medication was acquired at the hospital setting free of charge, but CGs disclaimed it was sufficient, so either the hospital would not provide enough pills for the entire treatment period, or wouldn't have availability of all of the medicines taken by the patient. This led to the interruption of the treatment and a sense of frustration by CGs:

"you see now, I have to get medicine [from the hospital] *after two weeks. One week, two weeks. Now you see, it has passed three weeks and I have not picked it" (P1)*

"I couldn't manage the money of that medicine because the medicine was so expensive, so he [PwD] *swallowed it for like one month and then he stopped" (P2)*

"I don't have money, he needs medicine all the time, I have to pick medicine" (P4)

"the other thing that disturbs us a lot is medicine, she [PwD] *no longer has medicine because it's expensive" (P11)*

From the sub-categories above, the experience of caregiving is followed by economic hardships caused by both an increase in the household expenses and a decrease in the income.

4.3 PERSONAL CARE

This category came as a summary of different aspects that CGs find to be challenging in the daily care required by the PwD. The main topics brought by the participants were related to *feeding*, *bathing,* and *handling excreta*. The degree of assistance required by patients varied based on the degree of cognitive decline. In some cases, the PwD was independent enough to bathe him or herself, whereas in other cases, the PwD was restricted to the bed and would require assistance while using a waste bucket, for example.

4.3.1 Feeding

Most participants described challenging situations while feeding the PwD. These challenges ranged from an increase in the PwD's appetite, leading to a need of cooking more often, to a concern regarding a decrease of food intake by the PwD:

"but feeding, not enough feeding" (P1)

"She [PwD] *reached a time and refused to eat and said that after all they told me that anytime am going to die, so why do I eat." (P5)*

"even if you cook what she [PwD] *wants she can't eat because she has spent three years without eating food. She has no appetite" (P11)*

"You have to keep feeding her [PwD] *so well. Because all the time, she is always hungry" (P3)*

Another situation described by CGs is the selective feeding, in which the PwD would only accept a certain type of food or meal. This was considered to be challenging by the CGs, since in some occasions the CG could not afford what was asked by the PwD, or in some other times, it would be disconnected to what the CG had already cooked, leading to a sense of "frustration":

"another problem, she [PwD] *doesn't want food with no soup, or with vegetables or like you cook tomatoes. She only wants to eat meat and fish and if you don't give that to her, she refuses the food and she spends the whole day and night without eating and yet you don't have money to go and buy for her good soup." (P9)*

"he [PwD] *doesn't like most foods, he wants Matooke, meat, fish and which sometimes I can't get because I don't have money" (P4)*

"she [PwD] *has some food that she selects, and she says I want this and this type of food" (P10)*

One last topic brought by participants was a need of further organization in the cooking routine, to have all meals set at a certain and predictable time. Even if the CG tried to make the routine more flexible, he or she would face some degree of stress in the feeding care, but still described for example as a minor, "small stress" when compared to the other struggles faced by CGs.

"or just eat lunch or supper and which you can't do to a patient, because whenever I try to delay a bit, she [PwD] *gets problems, yes so that is a small stress." (P5)*

4.3.2 Hygiene care

A considerable number of CGs was responsible for cleaning and helping the patient bathe. In the cases were the PwD could take a bathe in a more independently manner, the CG would be responsible to supervise the bathe, which was not considered to be a challenge by CGs. On the other hand, with an increase in the need for assistance, the challenges start to come and were described as convincing the patient to bathe and the difficulties related to undress the PwD:

"he [PwD] *refuses to bathe, I have to bathe him and cutting his hair" (P1)*

"bathing, she [PwD] *doesn't want to take a bathe. We sweet talk her slowly, slowly, and take her to the bathroom and even removing clothes… it's also a struggle" (P10)*

When it comes to handling the personal care and dealing with nakedness, there was a clear struggle when the gender of the caregiver and the PwD were not the same, leading to a sense described by CGs as "uncomfortable", reducing the autonomy of the CG while providing care:

"given that am a girl, I can't bathe him [PwD]*, because I am there alone and you can't tell him that bathe and he showers on his own so I have to get a grown up person when they are male and he bathes him" (P2)*

"he [PwD] *spends the whole day naked, which is not good for a girl to see or to look at. He doesn't want to dress up" (P2)*

"given that he [brother] *was a man, he couldn't look after her* [PwD]*" (P10)*

4.3.3 Excreta

A major discomfort described by participants was handling feces and urine. All the 15 CGs recruited for this study were responsible for handling excreta and brought this topic as a challenging one. The tasks varied from the disposal of the waste bucket, the lack of resources to buy diapers, the management of clothes, mattress and even the PwD when he or she could not reach the bathroom / bucket, along with cleaning the house because of excreta in inappropriate places, like floor and walls. The care in this area was compared to "having a baby" and described as "disturbing":

"He [PwD] *became like a baby in each and everything" (P14)*

"Because now every day I must wash, every day it's like I have a baby because when someone has a baby, they can't miss to wash cloths every day. So that whole situation that I pass in, is a challenge to me" (P9)

"sometimes you find when the feces have passed in him [PwD]*, when he has spoiled his clothes" (P2)*

"mother disturbs me a lot, now when dress her up, then she urinates and defecates in the cloths so all the time I have to wash. She even urinates and defecates on the bed and yet I don't have enough plastic sheet mattress cover... that finishes all the mattress" (P12)

"he [PwD] *urinates there, puts all the wastes there* [pointing to different directions]. […] *those things that he does, he urinates where he is, defecates where he is*, *even on the bed." (P4)*

Handling excreta was also associated with the CG feeling disgusted, especially regarding the smell:

"now the other thing you reach a time when you are disgusted because of that [waste] bucket that you take every day. […] *it is that bucket of wastes that is really my problem" (P2)*

"You have stools in your hands, and you feel disgusted" (P15)

"She [PwD] urinates on herself, nowadays she spits in her cloths and also in her hands and I mean she is always smelling" (P5)

As a result, the narratives uncover that the experience of caregiving is filled with obstacles related to personal care, such as guaranteeing a proper hygiene, handling excreta and assuring that the PwD will be properly fed. Considering the frequency CGs run into these tasks on a daily basis, these can represent a continuous source of discomfort and struggle.

4.4 INAPPROPRIATE BEHAVIOR

Participants describe their experience as challenging when it comes to handling inappropriate behaviors by the PwD. These inappropriate behaviors are presented as acts of physical violence and by improper conduct, such as undressing, damaging items at home and wasting resources / medicine.

4.4.1 Violence

A common topic addressed by participants is the struggle to handle aggressive behaviors by the PwD. This was especially true when interviewing a female participant. The aggression would usually come from the father or the husband. CGs argued they felt frustrated because they noticed the aggressions were motivated by minor and superficial events, like delaying a meal offered to the PwD or not fulfilling another trivial task. Sometimes, the aggressions didn't have any understandable cause perceived by the CG, who would fear the PwD:

"But I still worry and say maybe he [PwD] *might kill me in the house because given that his head is not well, you fear him, because sometimes you see when he has come like at night and I fear." (P4)*

"but now the problem he [PwD] *has, he reaches sometimes, and he gets crazy and when you try to talk to him, he just beats you" (P2)*

"the problems that I face…to get something to eat. That if you don't have what to eat or you take long to give him [PwD] *what to eat, he becomes aggressive" (P2)*

"there is also some other time when he [PwD] *wanted to beat me" (P4)*

"I called them [brothers] *and I told them that I'm leaving. The man* [PwD] *will kill me in this house" (P4)*

4.4.2 Incivility

Usually CGs describe challenges handling behaviors by the PwD that are not compatible with a life in a society, or that can increase the hardship in care providing. These behaviors include transposing other people's homes, being aggressive to neighbors, undressing publicly, screaming without any reason, and bringing trash to the neighboring houses:

"I have to be close to her [PwD] *so that she doesn't take anything dirty to the tenant's houses.* [...] *she enters in tenants and starts disturbing them and disorganizes their things. Sometimes she picks rubbish and she take it to their houses" (P12)*

"She became totally mad and she undressed, and she started entering into people's houses, beating the neighbors children and she became total mad." (P5)

"she [PwD] *can start undressing around the children" (P5)*

"mother became totally mad, she couldn't sleep, she used to undress herself, and she used to urinate on herself and even defecate on herself" (P12)

"sometimes she [PwD] *reaches a time and makes a lot of noises and she cries like someone they have beaten when there is nothing that has happened to her" (P12)*

4.4.3 Damaging and losing item

A common hardship brought by participants is when the PwD starts to damage the items at home, such as the mattress, the doors, walls, and wasting valuable resources such as water and food by, for example, pouring porridge into the floor, or spilling water:

"you have to be watching over her [PwD]. *And she also destroys things in the house. She might get like water and she pours it and pours detergent" (P12)*

"it affects me, now you see if a mattress was like this eeeeh like how you see this paper and she [PwD] *tears here and there, and also puts in a hole in it* [pointing to multiple hand-made holes in the mattress]. *So, the way it affects me is a person who has such a big mattress and you find that it's torn into pieces" (P9)*

"he [PwD] *would destroy things if I leave him in the house. Those things have challenged me a lot" (P14)*

"she [PwD] *started to really behave like a mad person, she used to hit the walls and she even broke some doors, we just repaired them again." (P9)*

Other times, it isn't properly food or water that is wasted, but medicine, frustrating the CG due to the high expenses and the effort made to purchase it.

"Because I give it [medication] *to her* [PwD]*, she pretends to take it and then spits it out. It's very frustrating." (P3)*

In some other occasions, CGs complain about when the PwD starts to hide things at home, like personal objects such as the cell phone, or money, or other important papers like prescriptions and bills. This leads to the PwD taking everything out of the place in the search for what was lost, or an effort by the CG to find the lost items:

"He [PwD] *will get a phone or anything in the house and hide it in his bed or in his pockets and you look all over for it when he claims he doesn't know where it is." (P14)*

From these sub-categories, the findings unravel that the experience of caregiving include the challenges related to the PwD's ability to live in society and in the family environment.

4.5 SAFETY OF THE PwD

Along the interviews, care providers declared a concern for the safety of the PwD. These concerns are mainly due to the possibility of the patient to get lost or run away, to be harmed by others and a concern for others taking advantage of the PwD.

4.5.1 Concern for the patient to get lost or run away

Participants stated a concern regarding the possibility of the PwD to get lost outside their home, especially when this has already happened previously and when the caregiver still keeps a regular activity outside the house, such as working or attending school, and therefore the CG is not directly responsible for supervising the PwD during these periods. This worries lead CGs to keep supervising the PwD through all times, which might be associated with a feeling of "frustration":

"So, watching over her [PwD] *all the time, but I don't complain about that so much because she is my parent, but just because sometimes you feel frustrated" (P5)*

"the other thing, even the other things that I want to do, I can't do them because he [PwD] *used to get lost and go, and he needs when I'm there because sometimes he used to go and get lost" (P4)*

"Sometimes if you don't watch her [PwD]*, she ran away" (P5)*

This concern impacts important life choices, for example, one CG expressed a desire to move to another house, but gave up on the idea because of the difficulties in finding a house that was fenced and hence could prevent the PwD from running away and getting lost. In another occasion, the CG chose to remain living in the same village where the local population already knows the PwD, so that in case the PwD gets lost, the caregiver can rely on the community to assist locating the PwD:

"The problem you might find there is what I also find once she [PwD] *has left, because she doesn't know where she is going. So when you get that problem you even don't know in what way you will get her, unless you go and people tell you 'we have seen your mother going here or there' and you also just go looking for her" (P9)*

"when people saw her [PwD] *they were like 'I think we know this lady'. That is when they called us. And they were like "we can see your mother here". I was telling them she had gotten lost." (P3)*

"they [neighbors] *help me a lot because those days she used to walk a lot and go far away but they used to tell me 'she is here, going here or there'" (P13)*
"but we are worried because this side she [PwD] *doesn't know this area very well" (P11)*

"But she [PwD] disturbs us a lot, in the morning she gets her belongings and tells us that she wants to go back home, so that meant that she didn't know where she was" (P5)

"she got lost and we spent the whole week looking for her [PwD]. [...] *I fear that she might get lost" (P10)*

4.5.2 Concern for the patient's integrity

Two of the participants explained that the insecurity regarding obtaining a governmental source of income while aging foster Ugandans to strive for a different source of income. A common form mentioned in the two interviews is the acquisition of land during the lifetime, that could be used for crops and harvesting when a person does not have the strength to keep working in more physically demanding areas. In this context, the participants mentioned the concern that the PwD who has obtained possessions could be turned into a target by other people who are interested in obtaining these lands through illegal means:

“they [other relatives] *do all means to get him away from me and kill him* [PwD]. [...] *I even have my neighbor, he is an army man and he helps me at night with the bodyguards, so that they don’t attack us.” (P1)*

“[other relatives] *have a mission to kill this person* [PwD] *because* [they have] *gone there and sold his properties* [PwD]*” (P1)*

“I first thought he had given him [PwD] *poison.* [...] *I called the Doctor very fast and he checked him and found that it was ok. So that’s when I started closing the gate and I got security” (P1)*

4.5.3 Concern for others taking advantage of the PwD

Participants expressed not only concerned about the physical integrity of the PwD, but also a concern regarding the possibility of other people taking advantage of the PwD, for example, expending all of the retirement money received by the PwD, or convincing the PwD to sign documents selling properties below the fair market price, leading to the loss of the PwD’s assets acquired throughout the lifetime.

“there are some misunderstandings between our stepmother [...], that is why she got a chance to sell all the things and finish them.” (P1)

“now when I went, I found his [PwD] *condition, they* [relatives] *have eaten the pension, even the house. The woman* [wife] *had even left the home and left him alone in the house.” (P1)*

“[the wife] *has sold land and no one has helped him* [PwD]*” (P1)*

From the category Safety of the PwD, the analyses show that the experience of caregiving includes a concern for the PwD’s integrity and wellbeing, since CGs believe they are responsible for providing those two.

4.6 PSYCHOLOGICAL DISTRESS

Participants describe a whole cluster of feelings and vegetative changes that indicate different degrees of psychological distress associated with care giving. The distress comes as a result of feeling overwhelmed and not having peers to share the care with, described as the withdrawal of other family figures from sharing the responsibility for care.

4.6.1 Sense of being overwhelmed

Caregivers mentioned that sometimes they believe the burden related to care providing has reached the vertex and became unbearable, pushing their personal limits and leading them to have second thoughts about keeping their role as CGs:

"you reach a time and feel that you are tired and feel like leaving him [PwD]. *Yes, you feel tired because I have so many problems, I look for money and even all those things that he does, and you feel when you are fed up" (P4)*

In this scenario, CGs described feelings of frustration, worry, being depressed and feeling like "a prisoner" in a situation they cannot change or escape from:

"so many things change… that you are worrying all the time. Your heart beats like its beating very, very fast" (P2)

"I think that all those are challenges, there is no positive thing that I get otherwise getting more depressed" (P9)

"I don't leave home, I'm like a prisoner" (P14)

CGs start then to question their own ability to provide care, becoming insecure on whether they will be capable of keeping on providing the necessary care to the PwD in the future:

"you think and ask yourself will I fulfill what I have to fulfill? Yes, I have finished taking her [PwD] *to hospital and to church but at home, will I fulfill what I have to fulfill?" (P5)*

4.6.2 Lack of Sharing the Care

Most participants complained about feeling neglected by the PwD's family, bearing alone the responsibility for the care. CGs stated that they were perceived by the other family members as the sole responsible for caring for the PwD, leading to the withdrawal of other family members' participation in care and hampering the possibility of sharing the burden of care providing with the rest of the family:

"but the relatives rejected him [PwD]. […] *The relatives don't care at all. Even if you call them and tell them this and that, they don't want to know" (P2)*

"even his family doesn't look after him [PwD]*" (P4)*

"they [relatives] *don't bring help, so they abandoned all [...] they even don't look after her* [PwD]*" (P9)*

"we [family] *are many and there is no one who helps me to bring help because they* [relatives] *see it is me who is looking after the patient" (P10)*

"I had a very hard time because I didn't get anyone, like among our relatives. I was here alone with her [PwD]*" (P13)*

"But as for his [PwD] *family, I have never seen them, and yet they are there and are so many, but no one has ever come" (P14)*

"they [relatives] *became more distant, no one wants to know" (P10)*

4.6.3 Sleep disturbance

Most participants described a change in the sleeping pattern due to care giving. This change is described as a difficulty into falling asleep during the nights. CGs provided different explanations to this same phenomenon. Some caregivers could not sleep at night because they were concerned about the PwD's safety or worrying about other problems related to care providing:

"yes, most of the times, I don't sleep because sometimes he [PwD] *wants to go out. So you are scared when you go to sleep and sometimes he comes and urinates in the corridor so I'd be listening to him all the time. You can't sleep a lot." (P4)*

"during the day you are awake, and the night you are awake" (P15)

"Sleeping sometimes you don't sleep enough because all the time you are worried about the situation [providing care]*" (P10)*

In some other cases, the reason that keeps the CG awake is a change in the behavior of the PwD, who also cannot sleep. Some CGs described a sense of sympathy, opting for remaining awake with PwD. In some other cases, CGs felt compelled to keep entertaining the PwD during his or her period of insomnia:

"I also feel bad when someone doesn't sleep, I also can't sleep. Even me I stay awake until morning" (P12)

"you can say that you are going to sleep that day and then she [PwD] *spends the whole night talking so I can't sleep, no, it's not possible. You have to spend the whole night awake until when she sleeps" (P6)*

4.6.4 Appetite changes

Less commonly than the change in the sleeping pattern, some CGs also described a shift in their own appetite behavior, usually leading to a decreased appetite and food intake as a result from the stress provided by care giving:

"Sometimes I'd be with him [PwD] *in that situation and I feel like I don't want to eat" (P4)*

"I couldn't do anything, and I even could fail to eat food." (P14)

The findings show that the experience of caregiving has an impact in CGs mental health and wellbeing, with vegetative disturbances, a sense of being overwhelmed and in some occasions the feeling that the CG is the sole responsible for the PwD.

4.7 POSITIVE ASPECTS

To attain another objective proposed by this study, which addresses the possible positive aspects related to caregiving, CGs were asked about their possible positive experiences in care providing. While describing the struggles related to caregiving seemed to be a more understandable task, being asked about the possible positive aspects of caregiving might have come as a surprise to some participants. In some cases, the question had to be repeated and rephrased. Many participants could not envision that there might be gains or a positive aspect in caregiving:

"if a person is sick, what good thing do you expect to get from her, me I think that instead of the good things, I you just get challenges. That's what I think that you get out of it, I don't think there is anything good you can get out of it" (P9)

"I don't have anything good that I have got from it [care giving] *because we have spent a lot of money to take care of her* [PwD]*, to see that her life is ok." (P11)*

"the good side? that I gain [in care providing]*? there is no way I feel good, you cannot admire the sick person. There is nothing good I feel. I had got hope when he* [PwD] *got better a bit and I became happy but now all of that disappeared" (P4)*

On the other hand, some participants brought spontaneously positive experiences related to care providing, as explained subsequently.

4.7.1 Sense of control

A positive experience covers a sense of being up to the task of care giving, feeling that the situation is enjoyable and manageable. In these cases, the challenges are still there, but the CG holds a feeling that the care giving situation is under his or her control, decreasing the impact of the burden of providing care:

"Taking care of her [PwD] *is not a burden to me because deep inside me I like it, and I feel that I can manage it" (P5)*

4.7.2 Blessings

Another positive aspect described by participants is having the belief of doing the right thing and feeling good about it. Moreover, participants believe that, because of their good actions, they were rewarded by a superior entity with blessings:

"what I feel I can get from it [care giving] *are blessings. Looking after her* [PwD]*, I feel good" (P10)*

"what good side? what I can say is I get blessings from God. It is the only thing" (P2)

4.7.3 Improving means

In some cases, especially when the CG and the PwD held limited means, becoming a CG could actually be perceived by CGs as a way to improve their lives by receiving donations from family, friends and neighbors, adding items to the household, which didn't happen before the person reached the status of a CG:

"the positive thing I have got is that, those days I used to stay alone, and no one used to give me things, but now I'm with her [PwD]. *I get things that come from different angles because I'm with her." (P10)*

4.7.4 Maturity

CGs describe that the experience of care giving has given them the chance to become more mature and develop a sharper sense of responsibility. The experience of care giving has galvanized participants into "thinking harder and working harder", along with "trying their best":

"That [caregiving] *was a wakeup call for me, to work harder and to think harder" (P3)*

"It [caregiving] has brought me maturity" (P7)

"It [caring] has helped me, actually. Helped me to be more responsible, to know that I have to do the best." (P3)

4.7.5 Social Bounds

Caregiving has also offered the opportunity for CGs to improve their social bounds, for example, becoming closer to family, friends, and the local community. Becoming a CG was described by participants as a lesson about the importance of building sustainable networks, to facilitate the care:

"I used not to share so much with people around. Now I must be friends with everyone around because sometimes he [PwD] *disturbs other people. So, I had to learn how to be social with everyone. I think this is positive." (P7)*

4.7.6 Learning

Participants described a sense of satisfaction while learning how to cope with the challenges related to care giving. CGs celebrated every new discovery and innovation about how to handle a certain situation as small victories that could improve their quality of life and the care offered to the PwD. In the case of Participant 15, who is the sole professional CG, the learning curve was considered to be especially important:

"It's a positive experience. You learn things at school, but now I'm starting to experience the real thing" (P15)

This category demonstrates that the experience of caregiving also embraces positive aspects. These aspects are related to a sense that caregivers can manage the role of caregiving, faith, the experience of improving the means, personal growth, strengthening of social bounds and the satisfaction brought by a sense that CGs are continuously learning about how to provide the best care.

4.8 COPING

Under the objective "to understand the coping strategies and support network used by the caregivers while providing care", the category "coping" emerged. This category consists of nine sub-categories, that combined bring light to the network system developed by caregivers, which is composed by family, friend's, community and health care support. This category also covers the CG's beliefs that contribute with coping, such as faith, sense of duty, hope for improvement and the sense that other people also endure care giving. Finally, it also comprises the lessons learned by CGs while caring that facilitate care providing.

However, the analysis of the interviews reveals a heterogeneity related to the establishment of coping strategies. While some participants managed to develop a robust support network and coping strategies, others felt they had to carry the burden of caregiving alone and failed to describe coping strategies:

"nothing, what do you think can make me strong, nothing" (P4)

The coping strategies and network system described by participants is explained in more details in the coming topics.

4.8.1 Family Support

While this is a controversial topic, once many participants described a lack of family support, those who could rely on their families experienced a strengthening of the family bounds and a decrease in the caregiving burden by sharing the care and the main decisions concerning the PwD. In these cases, the family plays an important role by helping to provide with financial means, along with actually sharing the care, for example, helping with the daily activities and supervising the PwD. The family also provides emotional support and the decisions regarding care are shared among the family members:

"I called all of them, the whole family. We make a meeting as a family" (P1)

"most of the times I also don't have enough money, so they [family] *also bring money and we buy medicine when I don't have enough money to buy medicine. So we have been working together." (P11)*

"my young brother. He is the one who usually gives us some help" (P2)

"When I'm off to work, they [children] *take care of her* [PwD]*" (P3)*

4.8.2 Friend's support

In some cases, it is not the family, but the friends that compose the CG's support system. The friends can be a source of help by sharing the care, for example, supervising the PwD while the CGs run other errands. Friends can also be a source of acceptance and emotional support, especially when CGs face stigma from other sources:

"the friends didn't reject us. Only the relatives rejected us. But the friends… we are very ok with them" (P2)

"I have a friend, when I'm not there, she will come and take care of her [PwD]*" (P3)*

4.8.3 Community support

More commonly, CGs rely on their neighbors and the local community for support. As explained previously, the villagers play a significant role when the PwD wander around and can't find his or her way back home. Sometimes, when the PwD walks for long distances, it is vital to have a network within the community to help finding the PwD. In these cases, a neighbor with a car is also a part of the solution, even if this person is not very close to the CG or PwD. The narratives show that there is a common sense of responsibility for caring shared by the local community. This support also includes the donation of food supplies to the household and money for the care expenses related to the PwD, such as donating money for the purchase of medicines and helping gathering money for commuting to the hospital. The villagers also provide other basic items related to care, like soap and pampers. Neighbors can also support the care in a more direct manner, such as overseeing the PwD sometimes. They can also contribute to the maintenance of the household, like making small repairs and help cleaning:

“they [neighbors] *give me social support, like that lady that I told you that she usually helps me. Let’s say* [PwD] *might need to be taken care of at the moment and then I’m sick, so she comes and helps me with cleaning” (P9)*

“sometimes you call in the village were mummy is and they send you food” (P2)

“the neighbors, they really helped me because they used to come and see him [PwD]. […] *People bring us sugar and rice” (P14)*

“My neighbors, they also give me food and they even help me collect for some money that I use to go to hospital" (P10)

However, the community support might be downturned due to the chronicity of the disease. Once villagers realize the condition might last for years with no significant change, the degree of support can decay, especially when it comes to donating money:

“at first when he [PwD] *had got sick when I was at home, like how you know village things, people would come and give you money. But now if people see that he is not dying, he is not getting better and he is not dying, eeehhh, people are also tired” (P4)*

4.8.4 Health care support

Caregivers find support in the health care network. The support encompasses medical appointments and exams that are vital for reaching a diagnose for the PwD and clarify to the CG where the problem lies, explaining the source of the symptoms observed previously by the CG. In some cases where the PwD is restricted to bed and the CG fails to commute to the hospital, the hospital staff organizes a home visit, so that the PwD can be evaluated and proper treatment established. The health care network is also imperative for the health care follow-up, checking the response and possible side effects to the medication. In some cases, the health care network will also provide the required medication free of charge:

"In the hospital, ok, I got some help even if they didn't explain to me what the problem was, but we went there, and I got help from medication" (P10)

"I get them [support] *here from the doctors, and whenever he gets a problem, here* [hospital] *is where I run to" (P4)*

"Support? Maybe from the hospital. I don't see any other support" (P8)

4.8.5 Faith

Participants described that a belief could help them cope with the challenges brought by caregiving. These findings come regardless of the faith professed by the CGs, since participants following Christianity, Muslims and local traditions experienced this sense of being comforted by their faiths. The faith comes as a belief that there is a superior being capable of end the disease of the PwD, or the challenges faced by CGs. The act of pray is also described as a source of relief to CGs, especially during the hard days:

"in my heart I don't want to complain to God because no one forced me to do it [caregiving]*, so sometimes when I see it wants to affect me, I start praying to God to give me strength so that I don't regret" (P5)*

"when I go to church and pray, I come back home feeling ok" (P1)

"but God is good, it [challenges] *will all come to an end" (P1)*

Having a faith can also provide the CG with a sense of reward, like the opportunity of receiving benefits from God due to the CG's good actions, care, and commitment towards the PwD.

"whenever I'm serving God in such a way [caregiving]*, I get energy inside me and I think that if I have done a good job even God will give me more* [years of] *life" (P5)*

"I believe God wants me to [care give]. *Because I believe God has something ahead for me* [reward]*." (P3)*

4.8.6 Sense of Duty

Another strategy for coping brought by participants is having the belief that there is a debt to the PwD, once usually this person is an elder who was responsible for raising the CG, like a parent or an older sibling. Usually, the responsibility is attributed to the eldest child of the PwD, or to the child who had the same gender as the PwD. Taking care of the parents or the partner plays an important role inside Ugandan cultural code system. In this scenario, the act of providing care is align with the caregiver's life beliefs and sense of own mission, arising a feeling of reward. There is a common saying in Uganda that states: "if you raise your children, and then they fail to look after you after you become an elder, then it was you who wasted your time raising them". These constructs work strengthening even more the sense of duty towards the elders:

"She [PwD] *is my mother, she looked after me for all those years, so why not give her the care she needs" (P3)*

"First of all, she [PwD] *is my mother. I have to persevere to the end. She took care of me when I was young, I have to take care of her now. I can't leave her with any other person. " (P8)*

"Since he [PwD] *is my dad, I can't turn the back on him.* […] *What helps me cope is the bond. The father and son bond." (P7)*

"that sister of mine [PwD] *was there for me a lot when I was young" (P13)*

"It's my responsibility. She [PwD] *is my mother" (P8)*

4.8.7 Hope for improvement

One attribute described by participants that help them continue with caregiving is the hope that the disease will come to an end, or at least the PwD will display any sign of improvement in his or her condition, becoming more independent. Participants describe that they get "energy" and "encouraged" when they see any sign of improvement, for example, when the PwD starts walking again, or regain the ability to feed without assistance. CGs also show an expectation to "get back to their old lives” following the recovery of the PwD, which is described as a motivational factor to reach the end of the day:

“the other positive thing that I think about is that if she [PwD] *gets better, I can leave her home and I go to my own home and I know that at home I have left there a grown person who is responsible.” (P10)*

“the good things I got is to see that she [PwD] *is getting better, yes that’s what I have got because if you look after someone and you see that she has not been eating and now she is eating, the one who has not been walking and see that she is walking. Then there you get the energy of continuing to take care of that person” (P6)*

“my expectations are for my mother [PwD] *to get better, to recover” (P8)*

“I hope one day he [PwD] *gets back to normal” (P7)*

“[…] *and go ahead and do what I need to do. Because I have hope that she* [PwD] *will be fine.” (P5)*

“what gives me hope is I see that there is a big difference that she [PwD] *has got compared to when she came here in and the situation she is in right now. So we see that she will become better.” (P11)*

“when I see what she [PwD] *does currently and what she was doing before, I get some hope” (P13)*

4.8.8 Sense that other people also endure caregiving

Knowing that other people also endure caregiving to a PwD provides a sympathetic feeling that the CG is not the only person in the world providing care, and if other people faced the challenges and were able overcome them, then overcoming challenges is also possible to the participant. The sympathetic feeling occurs not only when the participant actually knows a real person in the same situation, but the whole idea of having other people in the world facing the same struggles is comforting to the CG:

"When you know that the situation you are in, even some other people are facing them, it makes you stronger and I know that I'm not alone in this situation." (P10)

4.8.9 Learning how to care

During the course of caregiving, CGs developed their own strategies for handling the challenges associated with the day to day care and how to decrease the stress coming from these daily tasks. Through experience, they learned the best way to interact with the PwD, for example, convincing the person to shower or take the medicines. CGs described that a helpful resource was to become more organized, putting the tasks on a timetable that is predictable both to the CG and the PwD. This helps the CG to remember the activities, like giving medication and feeding the PwD on a regular basis. The predictability was also associated by CGs as means to decrease inappropriate behaviors by the PwDs once their needs would usually be met, with care offered on a regular interval, for example, changing dippers, exercising, and feeding:

"It helps me a lot to put her [PwD] *in a timetable that we are doing this and this even her taking medicine in time" (P13)*

"I have to plan on her [PwD] *schedule." (P3)*

"I'm enjoying what I'm doing because now I'm used to him [PwD]" (P15)

In addition to the strategies developed as resources for the daily care, the experience acquired along care giving has also shaped the relationship between CG and PwD in a more emotional and affective area. CGs learned that it is not sufficient only to attend the physical needs of the PwD, but that they should also show affection to the PwD:

"I learned that I have to be patient with her [PwD]. *Love her. Just show her that I care." (P3)*

"If you are too much strict on him [PwD], *it affects him." (P7)*

Coping is vital for developing a sustainable caregiving role that can overcome the many challenges already described along this study. From the narratives, the main resources that aid CGs to cope come from (a) external support (family, friends, community, health care), (b) faith, (c) the sense of duty derived from the dyad CG-PwD, (d) hope that the PwD will display signs of improvement and (e) knowing that other people have endured caregiving and overcame the challenges.

4.9 "IT'S MY RESPONSIBILITY"

Care giving is not an easy task. Even with the positive aspects that might arise from the care giving experience, the obstacles can be overwhelming and challenge CGs in different areas on a daily basis. After careful analysis of the data and consideration on all of the eight categories emerging from the narratives, the author uncovers that taking ownership on care giving is the driving force that leads people into committing to the role of caregiving, enduring the hardships and harvesting positive experiences. It is the sense of responsibility that drives CGs to hang on, to develop coping strategies and broaden their network, so that the care giving can be sustainable and CGs can fulfill their mission.

4.10 SUMMARY OF RESULTS

While exploring the caregiver experience in caring for a PwD, the narratives show that this experience starts even before a formal diagnose of dementia. Participants go through a process of understanding that there is something happening to the PwD, and hence try to explain the symptoms they observe based on their previous knowledge and cultural beliefs. The experience of caregivers pervades a process of understanding the disease, that might sometimes lead to a search for alternative possible solutions within religious leaders, churches, and local traditional cults.

Since the start of the symptoms and throughout the course of caregiving, participants face a wide range of challenges. These challenges start with an increase in the household expenses, targeting a diagnose and treatment of the underlying condition of the PwD. The increase in the expenses is combined with a change in the family dynamics, with the CG sharing his or her time between working and care giving, thus compromising the ability to work and the family income. Furthermore, CGs are challenged by the direct care provided to the PwD, handling the personal care, feeding, and supervising the PwD. CGs also need to handle the PwD's inappropriate behavior and are constantly worrying about the safety of the PwD. Commonly, CGs experience a sense that the caregiving experience is overwhelming, having an impact on their mental health, making them feel "depressed", and changing their sleeping and eating habits.

Some participants struggled to find positive outcomes in their experience as CGs. Other participants, however, claimed that care providing has brought them more maturity and responsibility, along with strengthening the social bounds and a sense of personal satisfaction in caregiving.

While describing their experience as care providers, participants argued for the need of more financial, emotional, and social support. There was also a need for more information regarding the disease and treatment, either from official sources, such as health care professionals, or exchanging practical information with other CGs. There is no support group for CGs or a PwD known by the participants, or any reliable source of guidance other than the medical care provided by the hospital. The information should also be disseminated throughout the community to decrease stigma.

Many participants allege they lack coping strategies and cannot find ways to decrease the burden related to caregiving. Those who described their current coping strategies mention the importance of the bound with the PwD, associated with a sense of duty towards the care receiver. Other coping strategies included having a faith and believing in a divine reward for caregiving, the belief that the CG can handle the caregiving situation and overcoming previous challenges through new insights and experience, the hope for improvement of the PwD's condition and a sympathetic feeling that other people have endured the caregiving situation. Another source of coping comes from the strengthening of the CG's network, relying on the help from the community, other family members and friends, along with a link to the health care system.

Through these analyses, the author uncovers the sense of responsibility as the underlying driving force that fosters CGs to provide the best care possible, enduring pitfalls and attaining their role as care providers.

The importance of these findings will be contextualized and further explained in the next section.

CHAPTER FIVE: DISCUSSION

5.1 DISCUSSION

With an increase in life expectancy, we can also expect an increase in age-related conditions, such as dementia (70). In this scenario, understanding the experience of caregivers of a PwD becomes the corner stone to understand the challenges, positive experiences and needs that come along the caregiving role and have an impact on caregivers' wellbeing and quality of life. In this context, this study contributed to an increased knowledge regarding the experience of caregivers as they provide care for a person with dementia (PwD) attending the outpatient facility at Butabika Hospital, Uganda. Accordingly, this study also provides information about possible areas that can be target by policy makers and addressed by the health care system.

The results presented along this work points to a journey through the establishment of the caregiving role. Becoming a CG finds its roots in the communal nature of Ugandan society, linked to the theme "it's my responsibility". The sense of responsibility leads to a sense of ownership by CGs, who commit to the role and communal expectations despite the possible challenges. It is also described in the literature that becoming a CG arises from a moral obligation (71), and this is especially norm in the traditional African context, where elders benefit from a hierarchical position of honor within the family and the community (72).

According to the present findings, the experience of caregiving starts from the point where caregivers try to give meaning to the symptoms they observe in the PwD, reaching a stage where a diagnosis and treatment are established, and then the future perspective CGs have, hoping for an improvement for the PwD and the possibility of going back to a scenario before assuming the caregiving role. The long path of caregiving, according to these results, is filled with obstacles that have an impact on caregivers' wellbeing. These hardships are linked to a societal organizational level, such as accessing medication, reaching the health care system, the lack of inducements to compensate for the decrease in the household income and the increase in the expenses and the information available about dementia and caregiving provided by official sources. Moreover, the data show that caregiving burden is also fraught with direct day-to-day care obstacles, such as supporting the PwD in his or her hygiene care and handling disruptive behaviors the PwD might present (agitation, aggression, disinhibition). These challenges, whether related to direct care or to socio-demographical conditions, are align with the current literature describing the difficulties CGs face and how these impact CGs' burden and wellbeing (73).

The experience of providing care for a PwD also allows for positive experiences. A recent integrative review composed by 41 articles displays these positive aspects as a multi-dimensional construct, which covers four key domains: a sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase of family cohesion and functionality, and a sense of personal growth and purpose in life (74). The results presented in this study are in agreement with these findings, with participants stating a rewarding sense by fulfilling their caregiving role and having the opportunity to reattribute the care to a meaningful elder / relative, a strengthening in the family bounds and the opportunity to become more mature with the caregiving experience. Moreover, this thesis adds to the importance of strengthening the community bounds as a positive aspect, once community plays an important role in Ugandan society and can be a source of financial and emotional support.

The data unravel that caregiving enables CGs to develop coping strategies that contribute to building resilience and finding ways of creating a sustainable caregiving role. Considering that dementia is a chronic and many times progressive condition, sustainability is vital for CGs to endure the possible many years to come performing the role of caregiving. In this context, sustainability allows for CGs to combine the caregiving role with other aspects of life, such as developing healthy social and familial ties and to find meaning in life. Moreover, sustainability in this case is the constant reminder that a person's identity goes beyond the caregiving role. Caregivers are still individuals with personal plans, hobbies and ambition that might conflict with the caregiving role and the energy and time required for caring. Finding a balance with the previous personal identity and the new acquired caregiving role is a step towards sustainability and the development of strategies for stress reduction and avoiding burn out.

The results of this study show that CGs rely on both emotion- and problem-focused strategies. The emotion-focused strategies in this study are based on religion / spirituality, the sense of fulfillment of a duty, keeping the hope for improvement and the inspiring sense that other people are successful in enduring the caregiving role. The use of emotion-focused strategies is associated with a decrease in symptoms of depression and anxiety by caregivers (75). In this study, the participants described problem-focused coping strategies, in which practical steps are taken to remove or reduce the stressor (75). Even though the support provided by family, friends, the community and health care system were a source of emotion-focused coping, these sources also allowed for the establishment of problem-focused strategies, as they provided the necessary resources to (a) do something about a possible problem-situation (76), and (b) planning, in which the caregiver tries to come up with a strategy about what to do, or thinks hard about what steps to take (77). The different sources of support added to the learning curve developed by CGs on how to handle the PwD's behavior made the daily care feasible. The analysis of the present data also allowed to detect an alleged lack of coping strategies by participants, especially in handling psychological distress. When feeling overwhelmed, some CGs didn't have a clear plan on what to do next or where they could get support from, leading to the development of feelings associated with depression and the inability to see a possible solution for the caregiving situation, arising a desire to withdraw from the caregiving role. However, dysfunctional coping behaviors, such as avoidance-focused strategies, were not elaborated on by the participants. The avoidance-focused coping strategy involves purposely avoiding activities related to a stressor, for example, through means of substance use or denial (78), and is associated with a significantly higher burden, decreased life satisfaction, and negative physical health outcomes when compared to problem and emotion-focused coping (79). The importance of understanding the coping strategies rests upon the evidence suggesting that coping is the most important predictor of caregiver psychological distress, irrespective of demographic or clinical characteristics of either the PwD or the CG (80).

5.2 IMPACTS OF THE METHOD

Choosing an appropriate method is a key point to generate adequate data and allow for a reliable, trustworthy analysis. However, when facing a qualitative design, there has been little consensus until recently on what constitutes a trustworthy study (65). While examining the current literature, three different perspectives arise to substantiate the grounds for quality assessment in qualitative studies (81). The first perspective evaluates the rigor based on positivistic terminologies, such as validity and reliability (82). The second paradigm, on the other hand, distances from the positivistic terminology based on the theoretical and philosophical differences found when comparing qualitative and quantitative research (83). Therefore, instead of reliability, internal validity, objectivity and generalizability, this second paradigm advises for the use of the terms dependability, credibility, conformability and transferability when assessing the quality of a qualitative study (83). Finally, the third paradigm advocates for the impossibility of a single pre-determined criterion for quality assessment, since qualitative research covers a wide set of research methods supported by different research theories and paradigms (81).

Regardless of the paradigm of choice, qualitative researchers should take measures to ensure trustworthiness in their research. In this context, Creswell (84) advises for the use of at least two different strategies for ensuring quality in any particular qualitative research. For this study, the author relies on self-description / reflexivity, peer debriefing and thick description.

The author is a Brazilian Medical Doctor with training in Psychiatry, more specifically in Geriatrics Psychiatry care. Therefore, handling patients with dementia and their caregivers in a middle-income setting has been her main activity for many years. This vast experience leaded to positive and negative outcomes, as she, at some degree, tried to find correlations between what she was observing during the interviews in Uganda and her past experience working with elders with dementia and their families attending outpatient facilities in Brazil. These experiences showed to be useful in connecting with participants and showing empathy. On the other hand, the same experience might have blinded the investigator to elements that are particular to the Ugandan setting and do not find a correspondent in Brazil. As means to try to decrease the negative impact and reflect upon any potential personal bias, the author used field notes and a reflective journal, as these are described as feasible means to reduce bias (85).

The second measure adopted by the author to ensure the quality of the study was peer debriefing (or "analytic triangulation") (86). In the course of this work, the author discussed the research methodology, data analysis and interpretations continuously with her two supervisors, who are experienced and skilled qualitative researchers. The debriefing provoked critical thinking and provided alternative/additional perspectives to the analysis throughout this thesis.

Lastly, to ensure external validity (transferability), the author provided sufficient details about settings, inclusion and exclusion criteria, sample characteristics and information about data collection and analysis method. The information provided allows for the readers to evaluate the extent to which the findings are transferable to other settings, situations and population (84).

5.3 IMPLICATIONS FOR PRACTICE

The findings in this study support the need for more information regarding the identification and management of dementia. The delay in searching for support within the health care system stalls the establishment of an early diagnosis, which could be beneficial for both the caregiver and the PwD. For example, an early diagnosis can identify and address reversible causes of memory loss (87). When the disease is expected to be chronic and progressive, an early pharmacologic intervention may slow the cognitive decline (88). Additionally, an early diagnosis provides time for patients and families to prepare for future care and maximizes patients' opportunities to contribute to the care planning process, thus, improving the wellbeing of both the PwDs and family members involved in their care (89). The need for information, especially in a community level, is vital for fighting stigma and raising awareness about the disease, preventing the isolation of the CG and the PwD and fostering community support (90).

The financial area also provides grounds for a governmental intervention. Facing the obstacles related to continuing working while caregiving, align with an increase in the household expenses related to caring, caregivers could avail of financial inducements by the government. CGs and the PwD would also benefit from receiving the medicines required for the treatment at a regular basis and free of charge, to prevent the interruption of the treatment due to lack of means.

According to the interviews, the treatment is solely based on a pharmacological approach and medically centered. The current literature shows benefits when the pharmacological and non-pharmacological treatments are combined, aiming to reduce the clinical progression and caregiving burden (91). As for the non-pharmacological approach, psychoeducation has a significant role in the management of caregivers' expectations, life and care planning needs (91). Psychoeducation can be defined as “an intervention with systematic, structured, and didactic knowledge transfer for an illness and its treatment, integrating emotional and motivational aspects to enable patients to cope with the illness and to improve its treatment adherence and efficacy” (92). Hence, psychoeducational programs, such as educational groups provided by a team of transdisciplinary professionals, including occupational therapists, psychologists, physiotherapists and social workers should be developed and provided for caregivers of PwD.

The non-pharmacological approach also opens the possibility for a multidisciplinary framework, relying on the support from physiotherapists, psychologists, and occupational therapists. There is evidence that strategies such as cognitive stimulation therapy, cognitive training and cognitive rehabilitation can promote gains in the cognition and degree of independence of the PwD, reducing the psychological distress associated with caregiving (93). Physiotherapeutic interventions can also promote a higher degree of independence and the ability to perform ADLs in PwDs, along with reducing other comorbidities that might have an impact on the PwD and on caregiving burden (94).

Finally, the study shows a need for interventions that aim to emotionally support caregivers, sustaining and guiding them throughout their caregiving role. In this context, the analysis shows that there is no support group known by CGs. The current literature also shows benefits in support groups for CGs of elders with dementia, which are considered an especially effective and economical way to relieve informal caregivers' stress and burden (95). Support groups are also means to promote education and share coping strategies, improving the wellbeing of caregivers (96).

5.4 FURTHER RESEARCH

Although there is an array of literature in the topic of caregiving for a PwD in a setting of high income, the literature investigating the experience of care providing in middle and low income settings is still limited, especially in the latter (97). More studies are required to investigate the experience of care giving in low-income settings to explore the impact of economic, educational and cultural variables in caregiving and caregivers’ wellbeing, and how these variables impact the development of coping strategies.

5.5 LIMITATIONS OF THIS STUDY

This is a hospital-based study with a small sample size which limits generalizability of the results to the general population of caregivers of people with dementia in Uganda.

The interviews had an average length of 54 min. However, one interview was an outlier, lasting for 27 min, whilst the range for the other 14 interviews was 40 to 98 min (55 min on average). Still, the author decided to add the outlier to the analysis, since the interview was still informative in some areas and could corroborate the other fourteen interviews.

Due to the lack of information in the patients' journal, it was not possible to stratify the patients regarding the type or the degree of dementia, which could have had an impact on the extent of care required and, therefore, the burden related to caregiving.

The study was based mainly on interviews that required translation from Luganda to English. Even though the prime investigator took measures in order to try to minimize bias due to the translation, the author is aware that some cultural or semantic information might have been lost in the process, since, as posed by Schopenhauer, all translations are “inherently imperfect” (98).

The language limitation, along with the obstacles related to commuting in Kampala, hampered the possibility for data triangulation with, for example, focus groups, since the access to participants was very limited, demanding extensive hours for commuting and some of them could not leave their homes. Group sessions were also unadvised due to the current Covid-19 pandemic.

5.6 CONCLUSION

The experience of providing care for a PwD is vast, starting from the identification of untypical behaviors to establishing a diagnosis and caregiving routine, filled with future expectations of improvement of the underlying medical condition. The path of caregiving for a PwD attending Butabika Hospital in Uganda is associated with a constellation of challenges that are deepened by social factors and welfare constraints expected from a low-income setting. Still, the experience of caregiving for a PwD also enables for positive experiences and the development of problem- and emotion-focused coping strategies.

This study added to the current knowledge by providing in details the challenges and positive experiences CGs run into, along with the possible coping strategies developed by them. Even though the setting of the study was a low-income country, the challenges were not restricted to the financial area, but also covered psychological aspects, such as psychological distress and constant worry for the patient's wellbeing. The analysis uncovers the facets of the positive experience of caregiving, revealing a sense of personal growth and fulfillment of personal mission, the alignment of the caregiving role with faith and the strengthening of social bounds. The results show that CGs of a PwD are subject to challenges and needs that can be aimed by policy makers and the health system and that are not directly dependent on improving the economic situation, but rather rely on social innovation. The data reinforces the need by CGs of accessing reliable and updated information about the disease and about how to handle, plan and facilitate the care. This information is not restricted to the pharmacological option, but the valuable insights that can be provided by other health workers. The results also show a fertile ground for the establishment of a support group, where CGs could exchange information about care and find emotional support among their peers. Coping was also addressed in this study, revealing the importance of the communal nature of Ugandan society and how personal beliefs and social bounding can be resources while building coping strategies. Through understanding CGs' experience of caring for a PwD, this study reveals the pathway into building a sustainable caregiving role. Reinforcing the positive aspects, targeting the challenges and meeting CGs needs constitute the triad that allows CGs to reach a healthy caregiving relationship towards the PwD.

Ultimately, the experience of caregiving for a PwD, enduring challenges, benefiting from positive aspects, and developing coping strategies is deeply affected by the communal nature of Ugandan society. Family (and extended family, such as some community members) is vital for Ugandan tradition, and CGs can endure the burden based on their belief that they are fulfilling their role. The expectation of fulfilling this role comes in a community, family and religious level (99). More importantly, the expectation come from CGs themselves – "it's my responsibility".

Even though this study added to the knowledge gap of caregivers' experience while caring for a PwD attending Butabika Hospital, more studies are required to better understand the experience of caregiving in low-income settings and how this care relates to quality of life and wellbeing among caregivers.

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APPENDIX I: CONSENT FORM (English Version)

Informed Consent Form for community members in Kampala, Uganda, and who we are inviting to participate in the research "Experience of caregivers while caring for a person with Dementia attending Butabika Hospital, Uganda"

Investigators

Lílian Juliane Kozlowski Mayerhofer
Norwegian University of Science and Technology – NTNU

"Experience of caregivers caring for a person with Dementia in Kampala, Uganda"

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

Dr. Lílian Juliane Kozlowski Mayerhofer, MD is working for the Norwegian University of Science and Technology. I am doing research on the experience of caregivers caring for a person with Dementia in Kampala, Uganda. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or another researcher.

Purpose of the research

Dementia is a disease that is increasing in the world, once the population has been living longer. The person with dementia can become very dependent on the caregiver to do daily activities, so understanding the experience of the caregiver can help us understand how this care is conducted, and what difficulties that the caregivers face. We want to learn what people who live or work here believe can cause the disease, how is their routine in terms of care and what they have learned works and doesn't work in terms of proving care. This knowledge might help us better understand the view of the caregiver and the bottlenecks in care.

Type of Research Intervention

This research will involve your participation in an interview that will take about one hour.

Participant Selection

You are being invited to take part in this research because we feel that your experience as a caregiver of a person with dementia can contribute much to our understanding and knowledge of the experience of care.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not.

Procedures

A. Provide a brief introduction to the format of the research study.

We are asking you to help us learn more about the experience of taking care of a person with dementia. We are inviting you to take part in this research project. If you accept, you will be asked to participate in an interview with myself and a Muganda trained in mental health and fluent in both English and Luganda.
During the interview, I will sit down with you in a comfortable place of your choice. If it is better for you, the interview can take place in your home or a friend's home. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer and the translator will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except me will have access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape. The tape will be kept on lock and key. The information recorded is confidential, and no one else except me will have access to the tapes. The tapes will be destroyed after three years.

Duration

The research takes place over 12 months in total. During that time, we will visit you once for interviewing you and the interview will last for about one hour

Risks

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics. However, we do not wish for this to happen. You do not have to answer any question or take part in the discussion/interview/survey if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

Benefits

There will be no direct benefit to you, but your participation is likely to help us find out more about how is the experience of taking care of a person with dementia in your community and what should be done to improve the support to caregivers and the person affected with dementia.

Reimbursements

You will not be provided any incentive to take part in the research. You will however be given 10,000 shillings for your time, effort and transport costs if any.

Confidentiality

The research being done in the community may draw attention and if you participate you may be asked questions by other people in the community. We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key. It will not be shared with or given to anyone.

Sharing the Results

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you before it is made widely available to the public. Each participant will receive a summary of the results. We will publish the results so that other interested people may learn from the research.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so. You may stop participating in the interview at any time that you wish. I will give you an opportunity at the end of the interview/discussion to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Who to Contact?

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact Dr. Anita Arinda on telephone number 0703742035.

This proposal has been reviewed and approved by the School of Medicine Research Ethics Committee, Makerere University, which is a committee whose task it is to make sure that research participants are protected from harm. If you have questions on rights of people taking part in the research, you can contact the chairperson of the committee responsible for rights of people taking part in research in School of Medicine, Makerere University, Associate Professor Ponsiano Ocama on 0772421190.

Part II: Certificate of Consent

I have been invited to participate in research about the experience of caregivers living with a relative with Dementia in Kampala, Uganda.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study**.**

Print Name of Participant__________________

Signature of Participant ___________________

Date (Day/month/year) ___________________________

If participant is unable to read and write,

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness ________________________________

Thumb print of participant ☐

Signature of witness _____________

Date ________________________
Day/month/year

Statement by the researcher/person taking consent
I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands what will be done.
I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this form has been provided to the participant.
Print Name of Researcher/person taking the consent________________________

Signature of Researcher /person taking the consent__________________________

Date ___________________________
Day/month/year

APPENDIX II: CONSENT FORM (LUGANDA VERSION)

Foomu y'okukiriza Oluvanyuma lw'okumanyisibwa

Foomu y'okukkiriza Oluvanyuma lw'okumanyisibwa eya batuuze mu Kampala, Uganda, era abo betugenda okuyita okwetaba mukunoonyereza okukwatagana no "Obumanyirivu bw'abalabirira ab'oluganda abalina ebulwadde bw'okuwuutta mu Kampala, Uganda"

Abanoonyerezi
Lílian Juliane Kozlowski Mayerhofer
Norwegian University of Science and Technology – NTNU

"Obumanyirivu bw'abalabirira ab'oluganda abalina obulwadde bw'okuwuutta mu Kampala, Uganda"

Foomu y'okukkiriza Oluvanyuma lw'okumanyisibwa erina ebitundu bibiri:

- Omuko ogunyonyola kukunoonyereza kuno.
- Ebaluuwa ekakasa kukkiriza (olwa kusaako emikono singa osalawo okwetabamu mukunonyereza kunno).

Ogya kuwebwa kkopi ya foomu ekakasa okukkiriza.

Ekitundu I: Omuko ogunyonyola

Enyanjura
Ndi Lílian Juliane Kozlowski Mayerhofer, MD, nkola ne ssetendekero wa sayansi ne tekinolegiya mu Norway atte Anita Arinda musoomi mu ssetendekero lya Makerere Mu Uganda. Bakola okunoonyereza kubumanyirivu bw'abalabirira ab'oluganda babwe nga balina obulwadde bw'okuwuutta mu Kampala, Uganda. Nina by'engenda okukubulira/okukunyonyola nga bikwatagana n'okunoonyereza kuno era nkusabe okwetabeemu. Totekedwa kusalawo olwaleero oba ogya, oba togya kukwetabamu. Nga tonasalawo, osobola okwogeramu n'omuntu yenna gwewesiga kubikwatagana n'okunoonyereza kuno. Foomu eno eyokukkiriza eyinza okubamu ebigambo by'otategeera oba by'otanyonyose bulungi. Nga tugenda mumaaso nga twogeraganya, nkusaba n'obuwombefu onyimirize, era njakutwala obudde nkunnyonnyole. Kunkomerero bw'obawo n'ekyobuuza, osobola okumbuuza oba okubuuza omunoonyereza omulala.

Omulamwa gw'okunoonyereza
Engeri nti kati abantu bawangala nnyo, endwadde y'okuwuutta nayo ebeera yeyongeera musi. Omuntu w'obulwadde bw'okuwuutta asobola okuba nga yesigama nnyo kubamulabirira okukola emirimu egyabuli bulijjo, n'olwekyo okutegera obumanyirivu bwa omulabirira kigya kutuyamba okutegera engeri okulabirira kuno gyekukolebwamu, era nabizibu ki abalabirira byebasanga. Twagala okuyiga abantu ababeera oba abakoola wanno byebakiriza nti biyinza okuleeta obulwadde bunno, enkoola yabwe eyabulijjo mukulabirira era biki byebayize nti bikola oba ebitakola mungeri y'okulabilira abalwadde bano. Amagezi gano gayinza okutuyamba okutegeera obulungi ebirowoozo byalabirira n'ebizibu mukulabirira.

Ekika ky'okunoonyereza
Okunoonyereza kujja kwetaagisa okukwetabamukwo mukubuzibwa okugya okutwala essawa nga emu yokka.

Okusunsula abanetabamu
Oyitiibwa okwetaba mukunonyereza kuno kubanga tulowooza nti obumanyirivu bwo nga alabirira omuntu w'obulwadde bw'okuwuutta kujja kwongeera kinene mukutegera kwaffe n'amagezi mubumanyirivu bw'okulabirira.

Okwetaba okwakyeyagalira
Okwetabakwo mukunonyereza kunno kwakyeyagalidde. Kiri gy'oli okwetaba oba nedda.

Emitendera
A. Nyonyola mubufunze engeri okunoonyereza gyekunatambulamu.

Tukusaba otuyambe okweyongera okuyiga n'ebikwatagana n'obumanyirivu mukulabirira omuntu wo bulwadde bw'okuwuutta. Tukuyita wetabe mumulimu gw'okunoonyereza kuno. Bw'okkiriza, ogya kusabibwa okwetaba mukubuzibwa nange awamu n'omuntu Omuganda eyabangulwa mu by'enddwadde z'omutwe ate nga amanyi bulungi oluzungu saako n'oluganda.

Mukubuzibwa kuno, njakutula wamu nawe mukifo ekikuwa emirembe. Bw'ekiba nga kirungi gy'oli, okubuzibwa kuno kusobola okubeera mumaka w'obeera oba mumaka gamukwanogwo. Bwewaberawo ekibuzo kyona ky'otayagala kuddamu, ntegeza, era abuuza agya genda kukibuzo ekiddako. Teri mulala yenna okuleka obuuza gatako n'omuvunuzi abagya okubeerawo, okuleeka nga wandyagadde omuntu oyo omulala okubeerawo. Eby'okwatibwa kulutambi byakyama, era teli mulala yeena okugyako nze agya kusobola kufuna ebyo ebiwandiikidwa nga obuziibwa. Okubuzibwa kuno kwonna kugya kutekebwa kulutambi, naye teri muntu yena ajja kumanyibwa olwokosesa erinyarye kulutambi. Alutambi lugya kusibwa awantu awekusifu. Ebikwatidwa kulutambi byakyama, era teri n'omu okuleeka nze agya okutukirira butambi. Oluvanyuma lw'emyaka essatu, obutambi bunno bugya kwononebwa.

Ekiseera
Okunoonyoleza kunno kujja kutwala emyezi 12. Mukiseera kino, tugya kkukyalira omulundi guno okubuuza era okubuuzibwa kugya kutwala essawa emu.

Eby'okwekengera
Ekizibu ekiriwo, oyinza okubulirako ebintu ebimu ebikwatako oba ebyekyama, oba oyiiza obutawulira bulungi kwoogera kumitwe egimu. Newankubadde kiri kityo, tetwandyadde kibeewo. Tolina kuddamu kibuuzo kyonna oba kwetaba mukubaganya ebirowoozo/mukubuzibwa/mukunoonyereza singa owuulira nti ebibuzibwa bikwatako nnyo nga omuntu oba nti okuby'ogerako kikumalako emirembe.

Eby'okuganyulwamu
Nga gwe tolina ky'ojja kuganyulwamu buterevu, wabula okwetabakwo mukunoonyereza kuno, kuyinza okutuyamba okweyongera okuzula kubikwatagana n'obumanyirivu mukulabirira omuntu wendwadde y'okuwuutta eyo gyobeera/owangalira era nakiki ekisobola okukolebwa okutumbula obuyambi obuwebwa abo abalabirira, okwo nga kwotadde n'omuntu akosebwa endwadde y'okuwuutta.

Eby’okuddizibwawo
Togya kuwebwaayo kasiimo konna olw’okwetaba mukunoonyereza. Ojja kuwebwayo shilingi za Uganda omutwalo kulw’obudde n’amanyi gotadde mu n’entambula.

Kukumibwa ngakyama
Okunoonyereza okukolebwa mukitundu abantu gyebabeera kukyayiinza okubaleetera okusayo omwoyo kuki ekigenda mumaso era bw’onetaba mukunoonyereza kuno abantu b’omukitundu kyo abalala bayinza okubuuza ebibuzo. Tetugya kubulirako muntu yenna atali mukunoonyereza kuno. Ebinakunganyizibwa byona mukunoonyereza kuno bijja kumibwa nga bya kyama/nkiso. Ebbikwatako bigya kuwebwa ennamba mukifo kyelinyalyo. Abo bokka abanoonyereza bebagya okumanya ennamba eyo era ebikunganyizibwa bigya kusibibwa awantu nekisumuluzo. Tebigya kubulirwako oba okuwebwa yeena gwekitakwatako.

Okumanyisa Ebivuddemu
Tewali nakimu kwebyo by’otubulidde olwaleero ekigya okumanyisibwako omuntu yeena ali wabweru wekibinja ekiri mukunoonyereza kuno, era tewali nakijja okwekusibwako nga kisinzidde kurinya lyo. Amagezi getujja mukunoonyereza kunno gagya kusooka kumanyisa gwe nga tebinafulibwa by’alukale. Buli eyetabye mukunoonyereza agya kuwebwa ebivuddemu mubimpimpi. Tugya kuubba mubitabo/mpapula ebivuddemu, olwo abantu abalala abetaaga basobole okuyigi kuva mukunoonyereza kuno.

Eddembe okugagana oba okukivamu
Tolina kwetaba mukunoonyereza kuno bw’oba toyagala kukikola. Osobola okuyimiriza/okusazamu okwetaba mukubuziibwa obudde bwonna woyagalidde. Nja kuwa omukisa kunkomerero okwekenenya eby’onoba oyogedde, era osobola okusaba okukyusamu oba okugyamu ebyo by’otakiriziganya nabyo mubyempandiise oba bwemba sikutegedde bulungi.

Ani ow’okutukirira?
Bw’obeera n’ekibuzo kyona, osobola okubabuuza kati oba oluvanyuma. Bw’oyagala okubaako ebibuuzo by’obuuza oluvanyuma, osobola okutukirira Musawo Anita Arinda kussimu 0703742035

Entekateka eno yekenenyezebwa era nekakasibwa aba kakiko ka School of Medicine akakwasa empisa, omulimu gwa kakiko kano kwekakasa nti abetaba mukunoonyereza tebatusibwako kabi. Okwekuusa ku mbeera y’ebyempisa mu kunoonyereza, tuukilira sentebe w’akakiiko akakwasisa empisa mu kunoonyereza akayitibwa ‘School of Medicine Research Ethics Committee, Makerere University; Omukenkufu (Associate Professor) Ponsiano Ocama, kussimu 0772421190.

Ekitundu II: Ebaluwa Ey’okakasa okukkiriza

Mpitidwa okwetaba mukunoonyereza okubikwatagana n'obumanyirivu bwa balabirira nga beera wamu n'owoluganda alina obulwadde bw'okuwuutta.
Nsomye ebyo ebiwandikiddwa oba ebinsomeddwa. Nfunye omukisa okubuuza ebibuzo ebikwatagana nekino era ebibuzo byonna ebimbuziddwa matidde nti mbizemu. Nkakasa nti neyagalidde okwetabakwange omunoonyereza kuno.

Erinya lyo __________________

omukono gwo ___________________

Ennaku z'omwezi ___________________________
(olunnaku/omwezi/omwaka)

Bwaba teyayitako musomero

Mbaddewo nga mubutuufu basoma foomu yokakasa okukiriza eriabo abasobola okwetaba mukunoonyereza, era omuntu ono awereddwa omukisa okubuuza ebibuuzo. Nkakasa omuntu ono awadde okukkiriza kwakyeyagalidde takakiddwa.

Erinya lyomujulizi ________________________________

Ekinkumu kyoyo owekwetaba mukunonyereza

Omukono gw'omujulizi _____________

Ennaku z'omwezi ________________________
(olunnaku/Omwezi/Omwaka)

Erinyo lyoyo anonyereza________________________

Omukono gw'oyo anonyereza__________________________

Ennaku z'omwezi ___________________________
(olunnaku/omwezi/omwaka)

APPENDIX III: SEMI-STRUCTURED INTERVIEW GUIDE (English Version)

Experience of caregivers living with a relative with Dementia in Kampala, Uganda

1. Could you please introduce yourself ?
    - Age
    - Sex
    - education level
    - occupation
    - marital status
2. For how long have you been taking care of Mr./Ms. …?

3. How did you find out that Mr./Ms. … had this disease?

4. Can you please share the difficulties you go through as you take care of Mr/Ms…?

5. Is there anything you wish was different in your daily care routine?

6. Have you had any positive experiences in taking care of Mr/Ms…..? If so, what were these?

7. Is there anything else you would like to add to this interview?

APPENDIX IV: INTERVIEW GUIDE (Luganda Version)

Obumanyirivu bw'abalabirira babeera nab'oluganda abalina ebulwadde bw'okuwuutta mu Kampala, Uganda

1. N'obuwoombefu nkusaba oneyanjurire era ontegeze oluganda lw'olina ku mwami/mukyala ………?
   - Ammanya
   - Ekitonde
   - Omulimu
   - Eby'okusoma

2. Omaze banga ki nga olabirira mwami/mukyala ………?

3. Wajja otya okumanya nti mwami/mukyala ……… ali eddwadde eno?

4. Biki eikusomooza bw'oba nga olabirira mwami/mukyala …………... ?

5. Waliwo ekintu kyona kyewandyagadde okuba ekyenjawulo mu byo byokola buli lunnaku nga olabirira?

6. Waliwo ebikusanyusa bw'oba nga olabirira Mwami/Mukyala…………?

7. Olinayo ekirala kyonna ky'oyagala okw'ongereza kukubuzibwa kunno

APPENDIX V: THEME, CATEGORIES, SUB-CATEGORIES AND CODES

It’s my responsibility	Knowledge about the disease	Causes of the disease	accident	witchcraft	punishment	aging	life style	loneliness
		Alternative search for help	Christian	local leaders	Muslim	healers	treatment	
		Information regarding the disease	Lack of info	doctors				
		Need for alternative sources of Information	Knowing other CGs	Knowing other PwD	friends	internet	neighbors	
		Stigma	shutting down	possession	madness	fingerpointing		
	Financial constraints	Decrease in the household income	working ability by the CG	working ability by the PwD	Covid-19			
		Increase in the expenses	buying personal care items	commuting to hospital	private care	buying medicines	exams	
	Personal care	Feeding	food selectivity	refusing to feed	organizing meals			
		Hygiene care	bathing	Gender incompatibility	nudity	undressing		
		Excreta	Feeling disgusted	Cleaning excreta	Spreading excreta			
	Inappropriate Behavior	Violence	physical agression	gender based				
		Incivility	undressing publicly	agression to neighbors	transpassing	screaming	moving trash	
		Damaging and losing items	wasting food	wasting medicine	destryoing things	hiding items		
	Safety of the PwD	Concern for the patient to get lost or run away	familiar environment	located by neighbors	evading the house	getting lost		
		Concern for the patient’s integrity	risk of murder					
		Concern for others taking advantage of the PwD	losing pension	losing properties				
	Psychological distress	Sense of being overwhelmed	unbearable	second thoughts	frustration	worry	depression	
		Lack of Sharing the Care	sole responsible	whithdrawal of others				
		Sleep disturbance	insomnia	awake with patient	concern	sympathy		
		Appetite changes	less appetite	food intake				
	Positive aspects	Sense of control	manageable	enjoyable	under control			
		Blessings	right thing	rewards	heaven			

		Improving means	donations	external help				
		Maturity	responsibility	becoming more mature	think harder	work harder		
		Social Bounds	closer to family	closer to community	closer to friends			
		Insights	overcoming challenges	learning curve	innovation			
	Coping	Family Support	lack of family support	emotional support by family	share decisions	financial help	share care	
		Friend’s support	help supervising	emotional support by friends	acceptance			
		Community support	finding the PwD	donating by villagers	supervising by villagers	repairing house	cleaning	not sustainable
		Health care support	medicines	medical appointments	exams			
		Faith	praying	relief	divine help	comfort	divine benefits	
		Sense of Duty	moral debt	personal mission				
		Hope for improvement	improvement	end of disease	regain ability			
		Sense that other people also endure caregiving	not the only one	others made it				
		Learning how to care	organization	predictability	affection			

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