



ST. PAUL'S HOSPITAL MILLENNIUM MEDICAL COLLEGE

DEPARTMENT OF PSYCHIATRY

**THE LIVED EXPERIENCES AND BURDEN OF CAREGIVERS OF PEOPLE WITH
DEMENTIA (MNCD): A QUALITATIVE EXPLORATION AT SAINT PAUL'S
HOSPITAL MILLENNIUM MEDICAL COLLEGE, ADDIS ABABA, ETHIOPIA, 2025**

INVESTIGATOR: DR. MICHAEL FREW (MD)

**ADVISORS: DR. BINIYAM TEHELKU (MD, ASSISTANT PROFESSOR OF
PSYCHIATRY)**

DR. MESKREM ABEBE (MD, ASSISTANT PROFESSOR OF PSYCHIATRY)

DR. SELAMAWIT ALEMAYEHU (MD, ASSISTANT PROFESSOR OF PSYCHIATRY)

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APPROVAL SHEET

This is to certify that the research entitled “The Lived Experiences and Burden of Caregivers of People with Dementia (MNCD): A Qualitative Exploration at Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025 EC ”is submitted in partial fulfillment of the requirements for the Specialty Certificate in Psychiatry to, Saint Paul's Hospital Millennium Medical College, Department of Psychiatry, and has been carried out by Dr. Michael Frew. Therefore, we recommend that the student has fulfilled the requirements and hence can submit the final research to the department.

Dr.Biniyam.Thelku

Name of Advisor 1 Signature

Date

Dr.Meskerm.Abebe

Name of Advisor 2 Signature

Date

Dr Selamawit Alemayehu



Name of Advisor 3 Signature

Date

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RESEARCH PROJECT SUBMISSION TEMPLATE

Name of investigator	Dr. Michael Frew
Full title of the research project	The Lived Experiences and Burden of Caregivers of People with Dementia (MNCD): A Qualitative Exploration at Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025 EC Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025 EC
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Address of investigator	Cell phone: +2510920244413 Email: michaelfrew37@gmail.com
Name of advisors	Dr. Biniyam Tehelku Dr. Meskrem Abebe Dr. Selamawit Alemayehu

LIST OF ACRONYMS/ABBREVIATIONS

DSM 5 TR	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revised
MNCD	Major nuerocognitive disorder
PwD	Patient with dementia
SPHMMC	Saint Paul's Hospital Millennium Medical College
USA	United states of America
UCLA	University of California Los Angeles
WHO	World Health Organization

ABSTRACT

Background: Dementia is a progressive neuro-cognitive disorder marked by substantial cognitive decline, interfering with daily activities. Globally, over 55 million people live with dementia, with approximately 60% residing in low- and middle-income countries. There is a scarcity of qualitative research that explored the lived experiences of caregivers in resource-limited settings such as Ethiopia. Understanding caregiver challenges is essential for designing culturally relevant interventions and policies.

Objective: To explore and describe the lived experiences of caregivers of dementia (MNCD) patients at Saint Paul's Hospital Millennium Medical College (SPHMMC), Addis Ababa, Ethiopia, 2025 E.C.

Methods: An exploratory phenomenological qualitative design was used among 10 purposively selected informal caregivers of people with dementia attending the psychiatry department at SPHMMC. Data were collected through semi-structured in-depth interviews until data saturation and analyzed using inductive thematic analysis with ATLASTi 7.3 software.

Results: Four major themes emerged: (1) physical and daily caregiving burden, (2) emotional, social, and financial burden, (3) knowledge gaps and unmet support needs, and (4) positive outcomes and coping strategies. Caregivers reported high-intensity, multidimensional challenges, yet demonstrated resilience, personal growth, and adaptive coping strategies.

Conclusion: Dementia caregiving in Ethiopia is characterized by profound multidimensional burdens compounded by limited formal support and low community awareness. The findings highlight the need for structured context-specific interventions, including facility-based caregiver education on dementia care and behavioral management, integration of psychosocial counseling into routine psychiatric services, community awareness initiatives to reduce stigma, and financial and respite support mechanisms to alleviate prolonged caregiving strain.

Keywords: Dementia; MNCD, Caregiver burden; Lived experience; Qualitative study; Ethiopia

1. INTRODUCTION

1.1 Background

Major Neurocognitive Disorder (MNCD) commonly referred to as dementia, is characterized by a significant decline in cognitive functioning that interferes with independence in daily activities. Affected domains include memory, language, executive function, and visuospatial abilities, representing a clear deterioration from prior functioning. Although “dementia” remains widely used in clinical and community settings, DSM-5 adopts the term MNCD to better reflect the spectrum of cognitive impairment and reduce stigma. The condition is typically progressive, with symptoms worsening over time, though the course may vary(1).

The concept of dementia dates back to ancient times, evolving from a view of normal aging to a recognized clinical condition by the 19th century. Key milestones include Alzheimer’s identification of pre-senile dementia in 1906 and advances in understanding during the 20th century(2, 3).

Four predominant types of dementia exist: Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. The most prevalent type is Alzheimer’s disease, accounting for 60-70% of all cases(4). It is marked by memory loss, disorientation, and difficulty in language, linked to the build-up of amyloid plaques and tau tangles in the brain(5). Vascular dementia, the second most common form, constitutes 5-10% of cases and is associated with cerebrovascular events like strokes, leading to impaired decision-making and motor dysfunction(6). Other less common causes include Lewy body dementia, Pick disease, frontotemporal dementias, normal pressure hydrocephalus, alcohol-related dementia, infectious dementias like HIV or syphilis, and Parkinson's disease(7).

A caregiver is an individual who provides sustained and direct support to a person who is unable to fully care for themselves due to illness, disability, or age-related conditions, often assuming responsibility for daily personal care, supervision, and health-related tasks over an extended period of time(6). Caregiver burden refers to the multidimensional impact of physical, psychological, emotional, social, and financial stressors arising from the caregiving experience(8). While caregiving involves providing support and assistance to loved ones, it does not inherently capture

the physical, emotional, and psychological stress experienced by caregivers; this distinction is particularly evident among caregivers of people living with dementia, whose prolonged and intensive caregiving responsibilities often result in significant distress and burden(9).

Informal care giving refers to unpaid care and support provided on a sustained basis by family members, relatives, or close friends to individuals with chronic illness or disability, such as dementia, without formal training or professional compensation and among informal caregivers(10). primary caregiver is defined as the individual who provides the majority of day-to-day care and support, often assuming ongoing responsibilities for personal care, medication management, and supervision of the person with dementia(10).

Caregivers often provide comprehensive support to individuals with dementia, going beyond basic daily tasks(11). They assist with activities of daily living such as bathing and dressing, as well as instrumental activities of daily living like managing finances and transportation(12). In addition to practical support, caregivers offer emotional comfort, coordinate with healthcare providers, and ensure the safety of their loved ones both at home and in the community(13). Caregiver burden leads to negative outcomes for caregivers, including depression, illness, and reduced quality of life, as well as adverse effects for dementia patients, such as diminished quality of life and earlier nursing home placement(14, 15).

In summary, Dementia is a progressive neuro-cognitive disorder characterized by declining cognitive abilities that interfere with daily functioning, with Alzheimer's disease being the most common type. The global burden of dementia is rising rapidly, particularly in low- and middle-income countries, including sub-Saharan Africa. As the condition advances, individuals increasingly rely on caregivers often family members who provide extensive physical, emotional, and practical support. However, caregiving is associated with significant burden, encompassing psychological, physical, social, and financial stressors.

1.2 Statement of the problem

Dementia is a progressive neurocognitive disorder characterized by significant decline in cognitive function, affecting memory, executive function, language, and visuospatial abilities, and interfering with daily life(13, 16, 17). Globally, over 55 million people live with dementia, with nearly 10 million new cases diagnosed annually, and the number is projected to triple by 2050, reaching 153 million, primarily in low- and middle-income countries(18, 19).In sub-Saharan Africa, the dementia burden is expected to rise by approximately 300% from 1.69 million people in 2015 to 5.72 million in 2050(17).

Dementia caregiving imposes a substantial burden on families and healthcare systems worldwide. Informal caregivers provide extensive unpaid care, valued at USD 271.6 billion in 2021, with the lifetime cost of caring for a person with dementia exceeding USD 377,000(6). Caregiving responsibilities encompass assisting with activities of daily living (ADLs) and instrumental ADLs, providing emotional support, coordinating medical care, and ensuring patient safety(20, 21).

Compared with caregivers of people without dementia, caregivers of individuals with dementia experience significantly greater emotional, physical, and financial challenges(22). Depression affects 30–40% of dementia caregivers, higher than among caregivers of individuals with schizophrenia (20%) or stroke (19%)(23, 24).Caregivers also face poorer physical health outcomes, including elevated stress hormones, compromised immune response, increased medication use, and cognitive decline (25, 26).

Several risk factors exacerbate caregiver burden, including patient-related factors such as behavioral and psychological symptoms, cognitive decline, incontinence, and functional dependency, as well as caregiver-related factors such as female gender, older age, lower education, and pre-existing health conditions(20, 24, 27-30).

In sub-Saharan Africa, the prevalence of dementia is increasing rapidly, from an estimated 2.13 million in 2015 to 3.48 million in 2030, potentially reaching 7.62 million by 2050, with over 367,000 new cases annually(19). This growing burden occurs within contexts of limited healthcare infrastructure, inadequate caregiver training, and socio-cultural barriers, including stigma and reliance on informal family networks, which amplify caregiver strain(4, 26, 31).Despite the rising

prevalence and severity of dementia, formal support systems remain minimal, leaving caregivers to cope largely on their own(29, 32).

In Ethiopia, national estimates indicate a dementia prevalence of 2.4%(33), though regional studies suggest higher rates, such as 43.8% of older adults in northern Gondar screening positive for cognitive impairment(34). Caregivers face overwhelming responsibilities, compounded by limited knowledge of dementia, scarce healthcare guidance, financial strain, and psycho social stressors(32). While international evidence highlights the effectiveness of interventions such as psycho education, structured support programs, counseling, and respite care in mitigating caregiver burden(8, 35, 36), there is limited implementation in Ethiopia, and little is known about caregivers' lived experiences in this context.

Despite global and regional recognition of dementia and caregiver burden, there is limited qualitative research exploring the lived experiences of dementia caregivers in Ethiopia, including their emotional, social, financial, and physical challenges, coping strategies, and unmet support needs. Understanding these experiences is crucial for designing culturally appropriate interventions and policies to support caregivers and improve dementia care outcomes. Therefore, this study aimed to explore the lived experiences and burden of caregivers of people living with dementia at Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia.

1.3 Significance of the Study

This study is important because it responds to a notable lack of evidence on the lived experiences of family caregivers of people living with dementia in Ethiopia. Although dementia caregiving places considerable demands on families, little is known about how caregivers understand the condition, how caregiving affects their daily lives, and what kinds of support they require. By exploring caregivers' everyday experiences, perceived burdens, and unmet needs, this study generates context-specific insights that are essential for understanding caregiving within the Ethiopian social and cultural setting. Such evidence is crucial for informing appropriate and responsive support strategies that can improve caregivers' well-being and sustainability of care.

From a clinical perspective, the findings of this study can help healthcare professionals gain a deeper appreciation of the challenges caregivers face beyond the clinical symptoms of dementia. Understanding caregivers' emotional, social, and psychological struggles enables clinicians to adopt a more holistic approach to dementia care, one that acknowledges caregivers as active partners in the care process. The study can also inform the incorporation of caregiver assessment, counseling, and guidance into routine clinical practice, thereby improving both caregiver support and patient care outcomes.

In addition, this study has important implications for policymakers and health planners. By documenting caregivers' unmet needs and the consequences of limited formal support, the findings highlight the necessity of developing caregiver-focused policies and services. These may include caregiver education and training, psychosocial support mechanisms, and financial or respite support options. Furthermore, this research contributes to the limited local literature on dementia caregiving and provides a foundation for future qualitative and quantitative studies in Ethiopia. Ultimately, the study aims to support evidence-based decision-making and encourage the development of comprehensive dementia care initiatives at both community and institutional levels.

2. LITERATURE REVIEW

2.1 Prevalence of Dementia

Globally, over 55 million individuals are currently living with dementia, with a significant proportion residing in low- and middle-income countries, and new cases continue to emerge at a rate of nearly 10 million annually(17)

Information on dementia prevalence in Africa is very limited. A systemic review of 10 relevant studies revealed that approximately 2.4% of adults over 50 in Africa were living with dementia in 2010, totaling around 2.76 million individuals, with the majority residing in Sub-Saharan Africa. Alzheimer's disease was the most common cause, accounting for 57.1% of cases, followed by vascular dementia at 26.9%(36). Sub-Saharan Africa is projected to experience a significant rise in dementia cases, with an estimated 2.13 million individuals affected in 2015, increasing to 3.48 million by 2030 and potentially reaching 7.62 million by 2050. Annually, over 367,000 new cases are diagnosed in the region. Sub-Saharan Africa is projected to experience a significant rise in dementia cases, with an estimated 2.13 million individuals affected in 2015, increasing to 3.48 million by 2030 and potentially reaching 7.62 million by 2050. Annually, over 367,000 new cases are diagnosed in the region(2, 37).

While the officially estimated prevalence of dementia in Ethiopia is 2.4%(33), research indicates that this figure may substantially underestimate the true prevalence. A study by Gela et al. found that nearly 44% of older individuals screened for cognitive impairment met the criteria for cognitive impairment. In another community-based cross-sectional study, conducted in June 2020, revealed a 42.1% prevalence of neuro-cognitive impairment among 423 randomly selected individuals(38), suggesting a higher prevalence than previously estimated.

2.2 Care giver burden

2.2.1 Global Perspectives

The prevalence of caregiver burden in dementia patients is a significant global concern, although exact prevalence rates vary widely depending on the region and study methodology(39).

A 2017 meta-analysis encompassing studies from China, the UK, the USA, Australia, and the Dominican Republic reported that approximately 49.26% of informal caregivers experienced

significant burden. Key stressors included time constraints, financial pressures, and social isolation, with behavioral symptoms in dementia patients, such as aggression, exacerbating the burden and increasing institutionalization rates(40). Similarly, a 2023 study at UCLA involving 307 caregiver-patient dyads highlighted the strain caregivers face. Nearly 40% of caregivers reported high levels of burden, with 15% experiencing moderate to severe depressive symptoms. Female caregivers were particularly vulnerable, reflecting broader gender-related disparities in caregiving responsibilities(41).

A 2024 systematic review analyzed 81 qualitative studies to understand family caregivers' experiences of dementia care. The review found both positive and negative aspects of caregiving. Positive experiences included personal accomplishment and strengthened relationships, often linked to adequate support. Negative aspects were prevalent, including financial strain, role conflicts, social isolation, psychological distress, and uncertainty about the future. These negative experiences were frequently associated with inadequate support, the progressive nature of dementia, and financial burdens. While this review provides a comprehensive overview, it may be biased towards negative experiences and includes studies with varying methodological quality(35).

2.2.2 Cultural and Contextual Influences

The impact of cultural and socio-economic contexts on caregiving experiences is evident. A 2002 qualitative study in India highlighted the significant burden experienced by young women, often daughters-in-law, who were the primary caregivers within traditional family structures. Behavioral problems and incontinence were major stressors, and caregivers experienced substantial emotional distress, including a reported case of caregiver suicide. This study underscored the critical need for improved dementia care services and education in developing countries, given the limited support from healthcare systems and other family members(42).

2.2.3 Caregiver Burden in African Contexts

Research in Africa underscores unique challenges due to limited healthcare infrastructure and social support systems. A 2024 scoping review analyzed six studies published between 2003 and 2018, exploring dementia care giving practices in four African countries (Nigeria, South Africa, Egypt, and Tanzania). The review found that caregivers were primarily unpaid, typically had

limited education, and spent significant time providing care. Caregiving experiences varied, influenced by cultural norms, individual circumstances, and limited support systems. Key challenges included lack of training, inadequate information, and insufficient support from both formal and informal sources. The review highlights the crucial need for improved dementia care in Africa, emphasizing the importance of educational programs, strengthening government support, and leveraging the role of religious and traditional leaders to enhance caregiver knowledge and support(43).

A 2020 cross-sectional study in rural Uganda found that 47% of caregivers scored above 60 on the Zarit Burden Interview, indicating severe caregiver burden. Gender differences were pronounced, with 49% of female caregivers and 43% of male caregivers experiencing severe burden. A positive correlation was observed between caregiver burden and symptoms of depression and anxiety, emphasizing the psychological toll of caregiving(44).

A qualitative study conducted in 2020 in rural Uganda explored the caregiving burden of both informal and formal caregivers of dementia patients. The study identified two main themes influencing caregiver burden: patient factors like problematic behaviors and physical health decline, and psychosocial and economic challenges including financial strain, family conflicts, and psychological distress. Formal caregivers primarily reported financial, interpersonal, and physical burdens, while informal caregivers described a wider range of burdens, including psychological challenges(45).

Further evidence of the multifaceted challenges faced by caregivers comes from a 2024 phenomenological study in Ghana(46). This study, while limited by a small sample size, revealed that caregivers experienced significant personal sacrifices, financial strain, stress, and even abuse. It also highlights that in settings like Ghana, dementia can be shrouded in myths, misperceptions, and spiritualism. However, alongside these negative experiences, some caregivers also reported a sense of purpose and strengthened relationships.

2.2.4 Ethiopian Context

A 2019 qualitative study conducted at Zeweditu Memorial Hospital in Ethiopia explored the lived experiences of six caregivers of people with dementia. The study, employing in-depth interviews, revealed that caregivers faced significant challenges, including limited dementia knowledge, overwhelming caregiving responsibilities, and severe psychosocial impacts such as stress, anxiety, and social isolation, using religiosity and support from other family members to cope. It also identified "not knowing the diagnosis" as one of the major themes from the caregivers' experiences. The researchers suggest this lack of understanding might stem from poor communication between clinicians and caregivers and the absence of psychoeducation during follow-up visits. While valuable insights were gained into the unique experiences of caregivers in this low-income country setting, the study's small sample size and limited participant diversity restrict the generalizability of the findings(47).

Overall, the literature highlights a growing global and regional prevalence of dementia, with a substantial caregiving burden affecting informal caregivers, particularly in resource-limited settings. Studies from various countries, including African contexts, show that caregivers frequently face psychological distress, role strain, financial difficulties, and social isolation. Despite these challenges, there is limited qualitative research exploring the lived experiences of caregivers, especially in Ethiopia. Existing studies reveal a lack of formal support systems, inadequate caregiver education, and unmet emotional and financial needs indicating a critical gap that this study aims to address.

2.3 Conceptual Framework

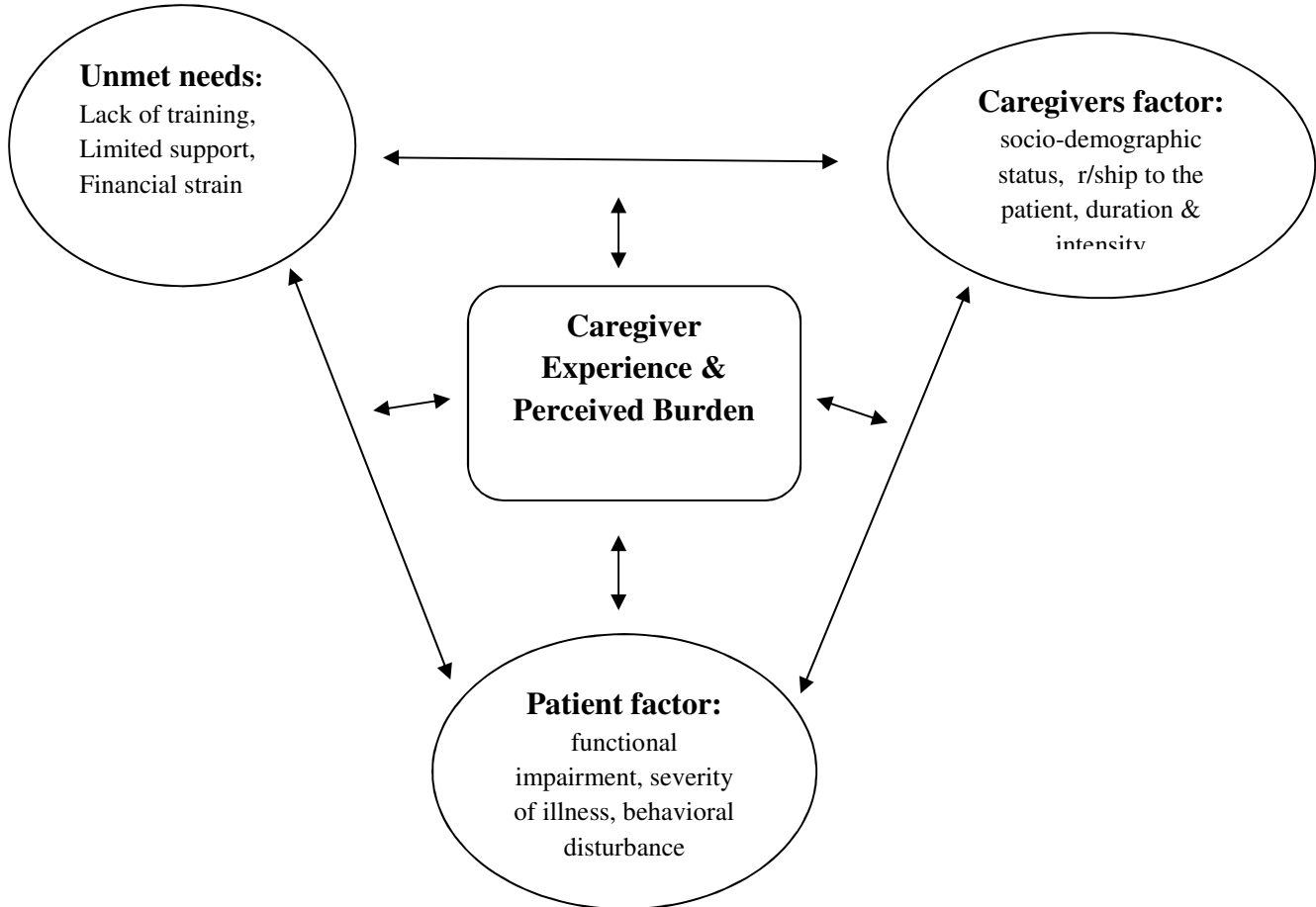


Figure 1: Conceptual framework illustrating the relationship between caregiver experiences with dementia patients and the associated risk factors (adapted from various studies(3, 12, 14, 31, 46)).

3. OBJECTIVE

3.1 General objective

- ❖ To explore and describe the lived experiences and burdens of family caregivers providing care to patients diagnosed with dementia (MNCD) at Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia, in 2025, using a qualitative phenomenological approach.

3.2 Specific objectives

- To examine the everyday experiences and practical challenges faced by family caregivers of individuals living with dementia at SPHMMC.
- To explore the emotional, physical, and social burdens that caregivers encounter while providing care at SPHMMC.
- To understand caregivers' knowledge, beliefs, and perceptions regarding dementia and its progression at SPHMMC.
- To identify gaps in support and the unmet needs of caregivers in fulfilling their caregiving responsibilities at SPHMMC.

4. METHOD AND MATERIALS

4.1 Study Area and Study Period

This study was conducted at SPHMMC, a government teaching hospital located in Addis Ababa, Ethiopia. The hospital was founded in 1976 and had grown rapidly since its establishment. The hospital had over 2,800 staff, including administrative and support personnel. The college primarily focused on medical teaching programs and offered many undergraduate programs with around 14 specialty departments and 16 sub-specialty training departments. The hospital was considered a catchment area for over 5 million people, and approximately 200,000 patients received services annually. The hospital provided both inpatient and outpatient services and had over 700 beds dedicated to admitted patients(50, 51).

The Psychiatry Department of the hospital provided inpatient and outpatient services. It had 27 beds for inpatient care, encompassing the acute ward, recovery ward, and substance ward. The outpatient unit was subdivided into regular, geriatric, substance, lithium, and pediatric clinics. The geriatrics OPD provided comprehensive outpatient care tailored to the unique needs of the geriatric population. On average, the OPD served approximately 670 patients quarterly, of whom around 93 were patients with dementia (MNCD).

The study was conducted from June to October 2025.

4.2 Study design

An exploratory descriptive phenomenological qualitative study design was employed. This approach was appropriate for gaining an in-depth understanding of the lived experiences of caregivers of dementia patients, capturing their perceptions, emotions, and challenges in a rich and detailed manner. The phenomenological method enabled the study to explore the essence of care giving experiences, emphasizing participants' subjective perspectives within their real-life context.

4.3 Population

4.3.1 Source population

The source population comprised all caregivers of patients diagnosed with dementia (MNCD) who were receiving care at the psychiatry or neurology departments of Saint Paul's Hospital Millennium Medical College (SPHMMC), Addis Ababa, Ethiopia.

4.3.2 Study population

The study population consisted of unpaid primary caregivers of dementia patients attending the psychiatry or neurology departments at SPHMMC. Participants were purposively selected based on the inclusion criteria to provide rich, in-depth insights into the caregiving experience.

4.4 Recruitment:

4.4.1 Inclusion criteria

- ✓ An unpaid primary caregiver of a person with dementia(PWD) (i.e., a family member, such as a spouse, adult child, or other close relative, who takes on the role of coordinating and managing the daily care needs of the PWD on a consistent and ongoing basis)
- ✓ An adult, that is, aged 18 years and above.

4.4.2 Exclusion criteria

Participants were excluded if they:

- ✓ Did not provide consent to participate in the study.
- ✓ Had significant communication difficulties that prevent effective participation in interviews.

4.5 Sample size determination

Ten participants were involved in semi structured interviews based on the selection criteria of participants until data saturation was reached.

4.6 Sampling Technique and Procedure

- ✓ A purposive sampling(52) method was employed to select participants who can provide rich, relevant, and diverse insights into the lived experiences of caregiving for individuals with dementia.
- ✓ In order to ensure variability and reduce sampling bias, participants were recruited from both the psychiatry and neurology outpatient departments of Saint Paul's Hospital Millennium Medical College (SPHMMC), Addis Ababa. Eligible caregivers who met the inclusion criteria was identified through patient records and consultation with treating physicians in both departments. Recruitment aimed to include caregivers across a range of characteristics (e.g., gender, age, relationship to the patient, duration of caregiving) to enhance thematic diversity.

4.7 Operational definition

Dementia(MNCD):A neuro-cognitive disorder diagnosed by a treating physician, characterized by a decline in cognitive function that affects daily living(6).

Caregiver: A family member, relative, or individual who frequently interacts with the patient and provides unpaid assistance in various forms, including financial, social, psychological, and physical support(12).

Primary Caregiver: The person who provides the majority of unpaid, day-to-day care and support to a dementia patient(48).

Caregiver Burden: The physical, emotional, social, and financial stress experienced by caregivers due to the responsibilities of caring for a person with dementia. In this study, caregiver burden was assessed qualitatively through semi-structured interviews exploring perceived stress and its impact(48).

Lived Experience: The subjective, personal account of caregiving as described by the caregiver, encompassing feelings, perceptions, thoughts, challenges, and meaning-making processes

associated with caring for a person with dementia. Lived experiences were explored using semi-structured qualitative interviews to allow participants to freely express their perspectives(13).

Unmet Needs: The caregiver's perceived lack of adequate resources, services, knowledge, or emotional/social support necessary for effective caregiving. These may include health system support, financial assistance, respite services, or psychological support that caregivers feel are needed but not received. Unmet needs were explored through semi-structured interviews, capturing participants' experiences in their own words and context(15).

4.7Data collection tools and techniques

Data were collected using in-depth, semi-structured interviews guided by an interview tool developed from relevant literature, clinical expertise, and standard texts in dementia care. The interview guide was initially prepared in English, translated into Amharic, and back-translated to ensure linguistic and conceptual equivalence. Prior to the main data collection, the tool was pretested with two eligible caregivers, and minor revisions were made to enhance clarity, cultural relevance, and flow. Interviews were conducted in a private and confidential setting, and all sessions were audio-recorded with participants' consent. Written informed consent was obtained from all participants before each interview commenced.

4.8 Data quality control

A trained research assistant (independent of the investigator) was responsible for recruiting participants and conducting the interviews using the semi-structured interview guide. The principal investigator handled transcription, translation, coding, and data analysis. This separation of roles helps reduce interviewer and confirmation bias(53).

4.6 Data Processing and Analysis

Data were collected in the Amharic language using audio-recorded in-depth interviews and transcribed verbatim before being translated into English by the primary investigator. To enhance data authenticity and minimize bias, techniques such as active listening, probing, and clarification were employed during data collection. The audio recordings and transcripts were reviewed repeatedly to ensure familiarity and accurate comprehension of participants' narratives. Data were then imported into ATLAS.ti version 9.3 for organization and analysis. Using reflexive thematic analysis as outlined by Braun and Clarke (2006; 2019)(54), the data were coded inductively and analyzed concurrently. Codes were iteratively reviewed and grouped into themes that captured patterned meanings across caregivers' accounts. All data were stored securely to ensure participant confidentiality.

4.13 Ethical consideration

Ethical clearance and approval for this study were obtained from the Institutional Ethical Review Board (IERB) of SPHMMC (ERC Ref No:PM23173). Following approval, formal permission letters were submitted to the hospital directors of SPHMMC, and data collection commenced only after official authorization from the college.

The confidentiality of all participants was strictly maintained throughout the study. No personal identifiers, such as names or contact information, were recorded in the data collection process. Informed consent was obtained from all participants after the purpose, procedures, risks, and benefits of the study were fully explained. Participants were informed of their right to refuse or withdraw from the study at any time without any negative consequences.

All responses were handled anonymously, and care was taken to ensure the privacy of participants during interviews. In cases where caregivers displayed signs of potential harm to themselves or others, the treating physician was promptly notified to ensure immediate and appropriate

intervention .The study adhered to the ethical principles of respect, beneficence, and justice, ensuring that participants' rights, dignity, and well-being were prioritized at every stage of the research process.

4.14 Result Dissemination Plan

The final thesis will be disseminated to the Department of Psychiatry. The finding will then be presented and defended, and then will be disseminated to SPHMMC, local authorities and MOH. The finding will be submitted to international journals for possible publication

5. RESULT

5.1 Socio-demographic Characteristics of the Study Participants

5.1 Socio-demographic Characteristics of the Study Participants

A total of ten primary family caregivers of persons living with dementia participated in the semi-structured in-depth interviews. All participants were directly involved in daily care provision and had sustained care giving responsibilities ranging from one month to six years. The caregivers' ages ranged from 19 to 65 years. The majority, 8(80%) were female. Most participants 7(70%) were married. Educational attainment ranged from primary education to higher education, with most participants 5(50%) having completed secondary school. The majority of the study participants 3(30%), were self employed. Most caregivers were immediate family members 6(60%), with daughters representing the largest group of caregivers in the study. The duration of caregiving varied, with several participants providing care for multiple years, indicating prolonged exposure to caregiving burden.

Caregivers reported spending substantial portions of the day providing care, often describing caregiving as a full-time responsibility. Duration of care giving ranged from one month to six years, with longer-term caregivers (≥ 3 years) consistently describing cumulative physical and emotional strain, heightened social isolation, and greater financial burden. In contrast, newer caregivers (< 1 year) highlighted initial adjustment challenges, learning caregiving routines, and managing acute behavioral changes.

Table 1:Socio-demographic Characteristics of Caregivers of Persons with Dementia at Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025 (n = 10)

P. C ode	Sex	Age(Yr)	Education	Occupatio n	Marital Status	Relations hip to patient	Comorbidity	Duration Of Care giving
P1	Female	39	Secondary	Self employed	Married	Daughter	None	4 years
P2	Female	50	Diploma	Unemployed	Married	Daughter	None	3 years
P3	Female	19	Collage	Self employed	Single	Daughter	Hypertension	1 year
P4	Female	19	Secondary	Hairdresser	Married	Daughter	None	1 month
P5	Female	45	Secondary	Unemployed	Divorced	Daughter	None	4 months
P6	Male	60	University	Government employee	Married	Brother	Stroke, HTN, DM	1 year
P7	Female	52	Collage	Retired teacher	Widowed	Daughter	Hypertension	6 years
P8	Female	40	Secondary	Self- employed	Married	Daughter	None	2 years
P9	Male	57	Primary	Farmer	Married	Husband	Diabetes mellitus	4 years
P10	Female	58	Secondary	Unemployed	Married	Wife	Hypertension	1 year

	n		

5.2 Main theme of the study

From the analysis of the interview data, fifty initial codes were identified and refined into four interrelated themes that collectively capture the lived experiences of dementia (MNCD) caregivers. Caregivers described their daily responsibilities as physically demanding and all-encompassing, including bathing, feeding, medication management, toileting, preventing wandering, and performing household tasks, often requiring 6–12 hours of direct care per day. Many participants reported minimal personal time, disrupted sleep, and physical strain manifested as back pain, headaches, muscle soreness, and general exhaustion, emphasizing the intensity of the daily care giving role.

In addition to the physical demands, caregivers faced substantial emotional, social, and financial challenges. Emotional burdens included stress, anxiety, sadness, guilt, frustration, and fears concerning the safety of the care recipient. Socially, caregiving responsibilities contributed to isolation, strained marital relationships, reduced family interaction, limited social engagement, and experiences of avoidance or judgment from friends and the broader community. Financial pressures further compounded caregiver burden, with participants highlighting lost income, reduced work hours, medical expenses, transportation costs, and limited financial support. These factors collectively underscored the profound multidimensional impact of dementia caregiving on caregivers' well-being.

Participants also reported significant knowledge gaps and unmet support needs. Many described limited guidance from healthcare providers, absence of formal caregiver training, minimal counseling, and lack of home-based care services. Community-level stigma and misconceptions, including beliefs that dementia reflects madness, spiritual punishment, or normal aging, further exacerbated caregiver challenges. Caregivers emphasized the urgent need for structured interventions, such as respite care, psychological support, financial assistance, caregiver training programs, and accessible home care services, to alleviate these burdens and enhance caregiving capacity.

Despite these challenges, caregivers identified positive outcomes and adaptive strategies that supported their resilience. Many reported increased patience, empathy, spiritual growth, and strengthened bonds with the care recipient. Coping strategies included prayer, emotional regulation, family and peer support, self-motivation, and acceptance of their caregiving role. These findings illustrate that, while caregiving is physically exhausting, emotionally taxing, socially isolating, and financially burdensome, it can also foster personal growth, relational strengthening, and resilience. The results highlight the urgent need for comprehensive support systems, including caregiver education, respite services, financial assistance, and community awareness programs(**Error! Not a valid bookmark self-reference.**).

Table 2: Themes and Subthemes Emerged from Qualitative Data Analysis on the Lived Experiences of Dementia Caregivers at Saint Paul’s Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025

Themes	Sub-themes
<i>Physical and Daily Caregiving Burden</i>	Daily caregiving tasks
	Time demands
	Physical strain
<i>Emotional, Social, and Financial Burden</i>	Emotional challenges
	Social impact
	Financial burden
<i>Knowledge Gaps and Support Needs</i>	Healthcare support
	Community perception
	Unmet caregiver needs
<i>Positive Outcomes and Coping Strategies</i>	Personal Growth
	Coping mechanisms

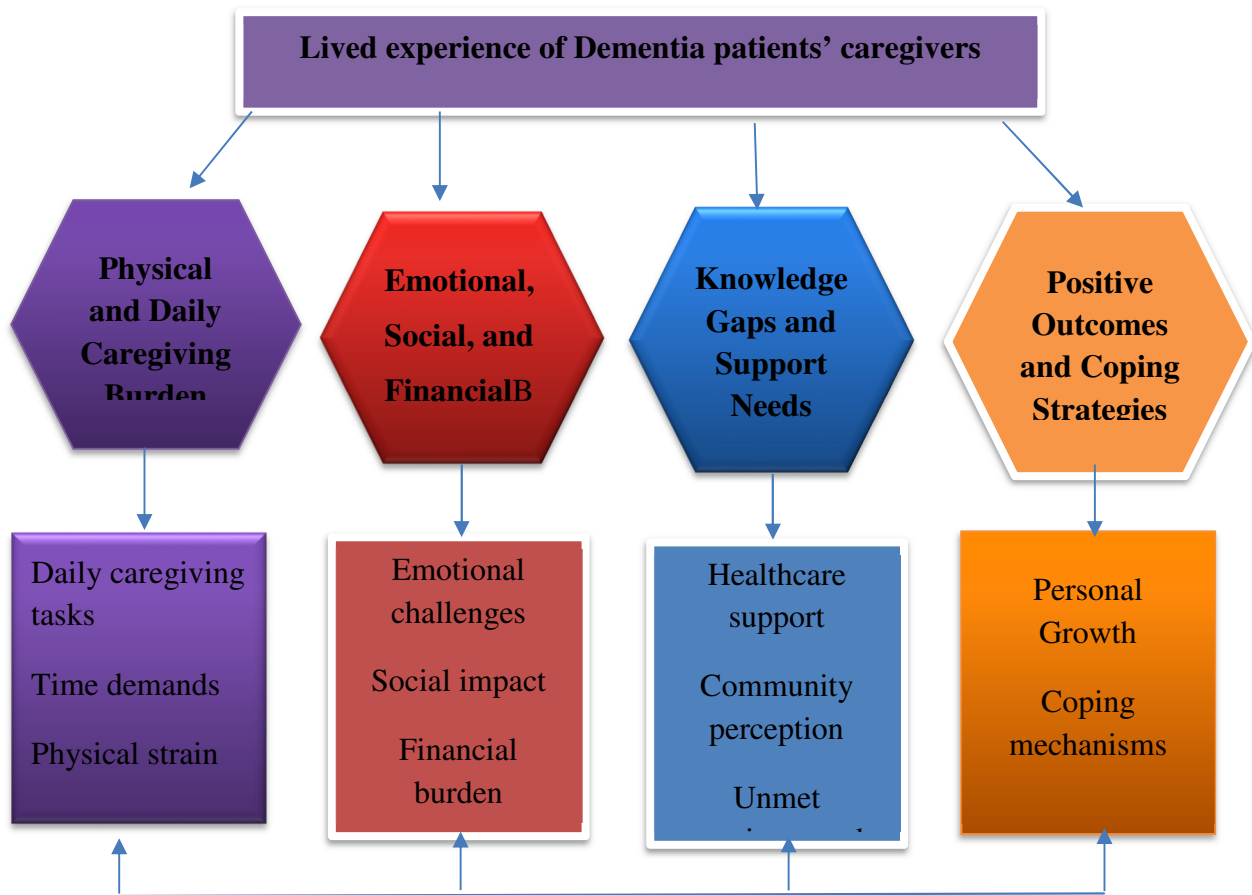


Figure 2: Summary of identified themes and sub-themes of Dementia Caregivers, in Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025

5.2.1 Theme 1: Physical and Daily Caregiving Burden

This theme reflects the intensive, hands-on nature of caregiving for persons living with dementia, as reported by participants. It encompasses the daily tasks required to maintain the care recipient's basic needs, the time commitment involved, and the physical strain experienced by caregivers. This theme includes codes related to bathing, feeding, toileting, administering medications, preventing wandering, performing household chores, continuous supervision, long hours of caregiving, fatigue, back pain, headaches, and sleep disturbances.

5.2.1.1 Sub-theme 1: Daily Care giving Tasks

Participants consistently described dementia caregiving as a demanding and all-encompassing responsibility that structured every aspect of their day. They performed a variety of essential tasks

including bathing, feeding, assisting with toileting, administering medications, preventing wandering, and providing continuous supervision. These duties were described not as occasional but as constant obligations dominating their lives. A clear pattern emerged showing that caregivers, especially daughters and spouses, are heavily involved in routine and high-intensity care, regardless of the duration of caregiving. Participants who had been caregiving for longer periods (≥ 3 years) reported more structured routines but also higher cumulative strain, while newer caregivers (< 1 year) emphasized challenges with learning caregiving routines and managing unpredictable behaviors.

One caregiver explained:

“My day starts very early. I bathe my mother, help her change clothes and diaper, prepare her breakfast, feed her slowly, give her medications, and stay close to her all the time. Even when I am cleaning or cooking, I am always watching her because she may fall or wander”(P01, Female, Daughter caregiver, 4 years’ caregiving experience).

Another participant similarly stated:

“I spend almost all day caring for my mother. I help her bathe, dress, eat, manage medications, and ensure she is safe. She recently became aggressive and refuses instructions, which makes caregiving very stressful”(P03, Female, Daughter caregiver, 1 year’s caregiving experience).

A third participant added:

“I prepare breakfast, check his medications, help him bathe and dress, and prevent him from leaving the house. I cannot leave him alone for more than a short time, even when I work”(P04, Female, Daughter caregiver, 1 month’s caregiving experience).

5.2.1.2 Sub-theme 2: Time Demands

Caregivers reported that providing care for persons with dementia (PWD) is highly time-intensive, often occupying nearly the entire day and night. Many participants indicated that their personal time was minimal, with caregiving responsibilities leading to sleep disruption, fatigue, and feelings of constant vigilance. Nighttime care was particularly challenging, as wandering, confusion, and aggressive behaviors of the care recipient required continuous monitoring. A clear pattern emerged in which long-term caregivers described cumulative fatigue and structured routines to manage care demands, whereas shorter-term caregivers focused more on initial adjustment difficulties and coping with unpredictable behaviors. The study also revealed gender differences, with female caregivers particularly daughters reporting more intensive daily and nightly engagement compared to male caregivers, consistent with existing literature on gendered caregiving roles.

One participant reported:

“I stay with my mother all day because I cannot leave her alone. If I leave, she tries to go outside. I do not get any free time; she needs constant attention” (P05, Female, Daughter caregiver, 4 months’ caregiving experience).

Another participant explained:

“Evenings are the hardest. She becomes restless and sometimes yells. I have very little personal time and feel guilty when I try to rest” (P07, Female, Daughter caregiver, 6 years’ caregiving experience).

Similarly, a male caregiver shared:

“I spend about 6 to 8 hours every day directly caring for my wife, sometimes more. My personal life is almost gone. Most of my time and energy are focused on her” (P09, Male, Husband caregiver, 4 years’ caregiving experience).

5.2.1.3 Sub-theme 3: Physical Strain

Caregivers consistently reported that providing care for persons with dementia (PWD) was physically demanding, often leading to musculoskeletal discomfort, fatigue, headaches, and sleep disturbances. Many participants acknowledged neglecting their own health due to the ongoing and intensive nature of caregiving. Physical strain was particularly pronounced for caregivers managing recipients with multiple comorbidities such as hypertension, diabetes, or stroke, as these conditions required frequent monitoring, medication administration, and rapid response to medical emergencies. The intensity of care demands suggests that both the complexity of the care recipient's health status and the duration of caregiving directly influence the level of physical burden.

One participant described:

“I feel very tired and exhausted. I cannot sleep the whole night because she wakes up and moves around. My back hurts badly from lifting her”(P01, Female, Daughter caregiver, 4 years' caregiving experience).

Another caregiver stated:

“I have back pain from helping her move and assist her with daily activities. I also have high blood pressure and trouble sleeping because I am constantly worried”(P03, Female, Daughter caregiver, 1 year's caregiving experience).

Similarly, another participant explained:

“Physically, I feel tired most of the time. Lack of sleep makes my body weak. I don't have time to care for my own health. I just continue because there is no other choice”(P10, Female, Wife caregiver, 1 year's caregiving experience).

5.2.2 Theme 2: Emotional, Social, and Financial Burden

The analysis revealed that caregivers lived experiences were profoundly shaped by intertwined emotional distress, social disruption, and financial strain, which together intensified the overall burden of dementia caregiving. While participants demonstrated deep commitment and responsibility toward their care recipients, the prolonged nature of caregiving, combined with limited external support, exposed caregivers to persistent psychological exhaustion, strained social relationships, and increasing economic vulnerability. These pressures not only affected caregivers' well being but also reshaped family functioning and future prospects. Participants providing long-term care (≥ 3 years) emphasized chronic emotional stress, persistent anxiety, and a sense of helplessness, particularly when caring for recipients with severe dementia and multiple comorbidities. The combination of prolonged caregiving and complex health needs intensified social isolation and financial strain.

5.2.2.1 Sub theme 1: Emotional Challenges

Caregivers consistently reported that providing care for persons living with dementia was emotionally overwhelming, generating persistent stress, anxiety, sadness, guilt, frustration, and emotional exhaustion. The emotional burden was heightened by constant worry about the safety and well-being of the care recipient, particularly concerning wandering, aggressive behavior, sleep disturbances, and sudden health deterioration.

Participants described feeling emotionally drained and isolated, with these challenges accumulating over time, especially among those providing long-term, continuous care without respite or professional support. Emotional strain was not only a response to the care recipient's symptoms but also reflected the caregivers' perceived inability to meet the complex demands of dementia care, often leaving them with feelings of guilt and inadequacy.

One participant described the emotional weight of caregiving as follows:

"Sometimes I feel very tired in my heart and mind. I worry all the time about what will happen to him whether he will fall or whether his condition will worsen. These thoughts never leave me"(P04, Female, Daughter caregiver, 1 month's caregiving experience).

Another caregiver expressed feelings of guilt and emotional helplessness:

“There are days when I feel sad and frustrated because no matter how much I try, his condition keeps changing. I blame myself and feel like I am not doing enough”(P09, Male, Husband caregiver, 4 years’ caregiving experience).

Similarly, one participant explained:

“I love my mother deeply, but sometimes the stress is too much. I feel exhausted inside, and there is no one I can talk to about what I am going through”(P01, Female, Daughter caregiver, 4 years’ caregiving experience).

5.2.2.2 Sub theme 2: Social Impact

Caregiving was reported to have profoundly altered caregivers’ social lives and relationships. Participants described social isolation, reduced participation in community and religious activities, strained marital relationships, and diminished contact with friends and extended family. Stigma and misunderstanding surrounding dementia further contributed to withdrawal and emotional isolation, as caregivers felt judged or avoided by others.

One caregiver stated:

“My friends stopped visiting because they don’t understand his illness. Some people think it is a curse. Because of that, I feel alone most of the time”(P07, Female, Daughter caregiver, 6 years’ caregiving experience).

Another participant shared the impact of caregiving on marital relationships:

“My relationship with my husband has changed. We no longer have time for each other because all our attention and energy are focused on caring for his mother”(P03, Female, Daughter caregiver, 1 year’s caregiving experience).

These social disruptions compounded emotional distress and reduced caregivers’ access to informal support networks that could otherwise buffer caregiving stress.

5.2.2.3 Sub theme 3: Financial Burden

The financial consequences of caregiving emerged as a major and persistent source of stress. Participants reported loss of income, reduced work participation, increased medical and medication expenses, and rising transportation costs. Many caregivers were compelled to stop working entirely or significantly reduce their income-generating activities due to the care recipient's dependence and need for constant supervision.

One participant explained:

“I had to stop working because she cannot stay alone. Hospital costs and transportation expenses keep increasing, and the money finishes very quickly” (P05, Female, Daughter caregiver, 4 months’ caregiving experience).

Another caregiver described the collapse of her livelihood:

“My business was affected badly after I became a caregiver. Whenever his condition changes, I leave everything to care for him, and that seriously reduced my income” (P10, Female, Wife caregiver, 1 year’s caregiving experience).

Together, these findings highlight that dementia caregiving imposes not only emotional and social costs but also substantial economic hardship, reinforcing the cumulative and multidimensional nature of caregiver burden.

5.2.3 Theme 3: Knowledge Gaps and Support Needs

The thematic analysis revealed that primary caregivers of people living with dementia frequently encountered significant knowledge deficits and unmet support needs, which profoundly influenced their caregiving experiences. Participants reported feeling underprepared to manage complex symptoms, behavioral changes, and medical tasks due to limited guidance from healthcare providers and the absence of formal caregiver training. These gaps heightened caregivers’ anxiety and uncertainty and contributed to feelings of inadequacy and isolation. Caregivers consistently emphasized the urgent need for structured education, accessible resources, and comprehensive support systems to sustain their caregiving roles effectively.

5.2.3.1 Sub theme1: Healthcare Support

A prominent finding from the study was that caregivers experienced limited guidance and support from healthcare providers in managing the complex needs of persons living with dementia. While some participants received basic instructions during clinic visits mostly focused on medication administration or routine tasks these were perceived as insufficient for addressing the day-to-day challenges of dementia care at home. The lack of formal caregiver training, counseling, and home-based services contributed to uncertainty, stress, and feelings of isolation among caregivers.

One caregiver explained,

“The health professionals tell me what medicine to give, but they never show me how to handle him when he wanders at night or refuses food. I just have to figure it out myself” (P03, Female, Family caregiver, 1 year caregiving experience).

Another caregiver similarly noted,

“There is no one to teach us what to expect or how to manage his behavior. Sometimes I feel completely alone in this” (P07, Female, Family caregiver, 6 years caregiving experience).

5.2.3.2 Sub theme 2: Community Perception

Caregivers also reported widespread stigma and misconceptions about dementia within the community, which limited social support and deepened their sense of isolation. Some community members misinterpreted dementia-related behaviors as madness, spiritual punishment, or normal aging, leading to judgment and avoidance. This social misunderstanding discouraged caregivers from seeking help and reinforced their marginalization. The study findings show how misunderstanding and stigma in the community can isolate caregivers, reduce social support, and intensify emotional distress. The finding suggests a pattern where caregivers are marginalized, not because of their caregiving abilities, but due to widespread misconceptions about dementia, such as beliefs that it reflects madness, spiritual punishment, or merely “old age.

One caregiver described,

“People in the neighborhood look at us strangely and think he is just crazy. They don’t understand dementia, and I feel ashamed and isolated” (P05, Female, Family caregiver, 4 months caregiving experience).

Another caregiver added,

“Even relatives sometimes say it’s just old age. They don’t want to help, so I am left to do everything alone” (P10, Female, Family caregiver, 1 year caregiving experience).

5.2.3.3 Sub theme3: Unmet Caregiver Needs

Participants emphasized unmet needs for practical and psychosocial support, including respite care, psychological counseling, financial assistance, and home-based services. Caregivers expressed that access to temporary relief, mental health support, or structured training programs would significantly improve their ability to provide quality care without compromising their own health. The absence of these resources forced caregivers to manage high-intensity caregiving demands with minimal guidance or relief.

One caregiver explained,

“If someone could come for a few hours to help me, I could rest and take care of myself. Right now, I have no one to turn to” (P01, Female, Family caregiver, 4 years caregiving experience).

Another caregiver stated,

“I wish there were classes or workshops to teach me how to deal with his memory loss and agitation. It would make things so much easier” (P08, Female, Family caregiver, 2 years caregiving experience).

A further caregiver expressed,

“Sometimes I feel overwhelmed. If there was financial support or counseling, I could manage better”(P04, Female, Family caregiver, 1 month caregiving experience).

5.2.4 Theme 4: Positive Outcomes and Coping Strategies

The findings indicate that despite the overwhelming physical, emotional, social, and financial challenges of caregiving, participants also described meaningful personal growth, strengthened relationships, and adaptive coping strategies that helped them sustain their caregiving roles. While caregiving was often exhausting and distressing, caregivers demonstrated resilience, emotional strength, and a deep sense of purpose that enabled them to continue caring for their loved ones. These positive outcomes and coping responses highlight the complex and dynamic nature of dementia caregiving, in which suffering and personal growth coexist. Interestingly, caregivers with extended caregiving experience also reported growth in patience, empathy, and problem-solving skills, suggesting that prolonged engagement, while burdensome, may foster resilience, especially among those managing multiple health challenges in their care recipients.

5.2.4.1 Subtheme 1: Personal Growth

Participants frequently reflected on how caregiving had transformed them emotionally and spiritually. Many reported developing increased patience, empathy, emotional maturity, and resilience, alongside a deeper understanding of responsibility and compassion. Several caregivers described a sense of spiritual growth and personal fulfillment that emerged through caring for their loved ones, despite the hardships involved.

One caregiver explained,

“Before this, I was very impatient. But now I have learned to stay calm, to understand, and to accept things as they are. Caring for him changed my heart”(P02, Female, Family caregiver, 3 years caregiving experience).

Another caregiver shared,

“This experience has made me stronger. I never knew I could handle so much. Even when I am tired, I feel proud that I am doing something meaningful”(P06, Male, Family caregiver, 1 year caregiving experience).

A further caregiver reflected,

“I feel that God is shaping me through this responsibility. It has brought me closer to my faith and taught me many lessons about life”(P09, Male, Family caregiver, 4 years caregiving experience).

5.2.4.2 Sub theme 2:Coping Mechanisms

This sub-theme encompasses the strategies caregivers use to manage emotional distress, sustain motivation, and adapt to the challenges of providing care for a person living with dementia. The findings show that caregivers actively develop coping mechanisms to navigate the physical, emotional, social, and financial burdens associated with caregiving, reflecting their resilience and ability to adapt to prolonged stress. Caregivers described a variety of coping strategies, including prayer and spirituality, emotional regulation, family and peer support, self-motivation, and acceptance of their care giving role. Spiritual practices, particularly prayer, were commonly cited as a source of psychological strength and inner calm, helping caregivers endure daily care giving responsibilities. Emotional support from family members and peers also served as a buffer against stress, providing an avenue for sharing experiences and relieving psychological tension. Acceptance of the caregiving role emerged as an internal coping strategy, enabling caregivers to maintain focus and reduce feelings of helplessness.

One caregiver stated,

“When I feel overwhelmed, I pray. It gives me peace and helps me continue”(P05, Female, Family caregiver, 4 months caregiving experience).

Another caregiver noted,

“Talking with my sister helps me a lot. When I share my problems, I feel lighter and stronger”(P01, Female, Family caregiver, 4 years caregiving experience).

A further caregiver explained,

“Sometimes I just remind myself why I am doing this. Accepting the situation helps me control my emotions and move forward”(P08, Female, Family caregiver, 2 years caregiving experience).

6. DISCUSSION

The findings demonstrate that dementia caregiving in this Ethiopian psychiatric context is a prolonged, intensive, and multidimensional experience characterized by substantial physical burden, emotional distress, social isolation, financial hardship, and significant unmet support needs. At the same time, caregivers reported personal growth, resilience, and culturally grounded coping strategies. These findings align with and extend evidence from studies conducted in Hong Kong, Singapore, China, Ethiopia, Uganda, Tanzania, Nigeria, Ghana, Kenya, and South Africa(13, 45, 55-59).

6.1 Physical and Daily Caregiving Burden

Caregivers in this study characterized dementia care as highly labor-intensive and time consuming, requiring sustained assistance with fundamental activities of daily living including bathing, feeding, toileting, medication administration, and continuous supervision to prevent wandering often for 6–12 hours per day. Comparable levels of intensive family caregiving have been documented in studies from China, New Zealand, and Addis Ababa, where the limited availability of formal long-term care services necessitates that family members assume primary responsibility for comprehensive dementia care(32, 59-61).

Similar experiences have been reported in studies from New Zealand, Indonesia, Uganda, and Nigeria, where caregivers described long hours of physically demanding care, constant supervision, and exhaustion as dementia symptoms progressed(61-63). In rural South Africa, caregivers likewise reported significant physical strain related to lifting, disrupted sleep, and the need for continuous vigilance, particularly when caring for individuals with more advanced stages of the disease(63).

Most of the participants reported experiencing physical health symptoms. The physical health consequences identified in this study including musculoskeletal pain, persistent fatigue, and sleep disturbances are consistent with evidence from Singapore, Uganda, and Nigeria, where prolonged care giving in the absence of respite has been linked to chronic physical discomfort and neglect of self-care(58, 62). By contrast, studies from South Africa suggest that even limited access to community-based support services can reduce physical strain among caregivers, which may account for lower reports of severe exhaustion in those settings(64). The lack of comparable

support structures in Ethiopia therefore offers a plausible explanation for the pronounced physical burden experienced by caregivers in this study.

The current study also shows that most of the participants those supporting individuals with dementia and coexisting chronic comorbidities experienced additional physical and cognitive demands beyond routine dementia care, including regular monitoring of vital signs, managing complex medication regimens, and responding to acute medical events. This pattern is consistent with findings from studies conducted in the United States, Uganda, and Nigeria, which report increased physical strain and a higher risk of caregiver burnout among those caring for patients with multiple chronic conditions(65, 66). Furthermore, the association between longer caregiving duration and cumulative physical fatigue underscores the importance of structured respite services to reduce long-term caregiver burden and protect caregiver health.

6.2 Emotional and Psychological Burden

Participants in this study experienced substantial emotional strain, manifested as persistent stress, anxiety, sadness, guilt, frustration, and emotional exhaustion. Comparable emotional challenges have been documented among caregivers of persons with dementia and severe mental illness in Ethiopia, where prolonged caregiving responsibilities and uncertainty surrounding disease progression contribute to sustained psychological distress(32).

Similar patterns have been observed in studies from Japan, Tanzania, and Kenya, where caregivers reported ongoing worry, emotional fatigue, and feelings of helplessness arising from behavioral disturbances and the unpredictable nature of dementia care (67-69). In Ghana and Nigeria, caregivers additionally expressed guilt and self-blame when they perceived themselves as failing to meet caregiving expectations, a response strongly influenced by cultural norms emphasizing filial obligation and marital responsibility (70).

While some studies from rural Japan, Ghana report restrained emotional expression due to cultural normalization of suffering, caregivers in this study articulated emotional exhaustion openly(69). This difference may be due to the hospital-based psychiatric setting in Addis Ababa, where caregivers may feel more permitted to express psychological distress compared to community contexts(57).

According to this study, caregiving duration and the presence of comorbidities were notable modifiers of emotional distress. Long-term caregivers, particularly those managing recipients with multiple chronic illnesses, experienced persistent anxiety, guilt, and depressive symptoms. This aligns with prior evidence from studies in China (59), Uganda (66), Japan (69), and Ghana/Nigeria (70), suggesting that prolonged exposure to caregiving tasks, compounded by complex health needs, exacerbates emotional burden and heightens vulnerability to mental health challenges. Moreover, the emotional toll on caregivers is frequently intensified by factors such as limited social support, financial strain, and the physical demands of caregiving, collectively increasing their susceptibility to psychological distress.

6.3 Social Isolation, Stigma, and Cultural Interpretations of Dementia

The current study also revealed that social isolation and stigma were prominent experiences among caregivers of persons with dementia. Many participants described feeling excluded from community activities, experiencing strained marital relationships, and perceiving avoidance or judgment from neighbors and extended family members. Several caregivers expressed that community members often interpreted dementia symptoms as madness, spiritual punishment, or simply normal aging, which intensified their sense of isolation.

Similar patterns have been reported in studies from southwest Ethiopia and northern Tanzania, where cultural interpretations of dementia contributed to social distancing and negative judgment of caregivers(40, 71). Caregivers in the United Kingdom and Nigeria also described experiences of stigma-related isolation and hesitancy of neighbors and relatives to engage with persons living with dementia, highlighting that this is not only a local phenomenon but a cross-cultural challenge(4, 72). In South Africa, stigma has been shown to limit community support despite relatively greater awareness of mental health conditions(73).

Interestingly, while studies from Ghana note robust extended family involvement in caregiving, participants in this urban Ethiopian setting frequently reported limited support from relatives(57). This difference may be explained by urbanization, economic pressures, and evolving household structures in Addis Ababa, which restrict the availability of extended family caregivers despite ongoing cultural expectations that family members assume primary caregiving roles. However,

some participants described occasional assistance from extended family members, suggesting that traditional support networks persist amid these challenges, albeit in limited forms.

The misinterpretation of dementia symptoms as witchcraft or a curse can further disrupt these familial support systems, leading to stigmatization and social exclusion of both the person with dementia and their caregiver, as observed in studies from Nigeria and Tanzania (71).

6.4 Financial Burden and Economic Vulnerability

The current study also revealed that caregivers experienced substantial financial strain. Many reported loss of income, reduced employment opportunities, and escalating costs related to medical care and transportation. Participants explained that the demands of caregiving often interfered with their ability to maintain income-generating activities or small businesses, leading to economic hardship.

These findings are consistent with studies from the United Kingdom, Ethiopia, Uganda, and Nigeria, where caregiving responsibilities frequently forced family members to leave employment or reduce working hours, while ongoing medical expenses depleted household resources(12, 45, 72, 74).

In Uganda, caregivers of persons with dementia reported leaving employment due to the need for constant supervision, while Nigerian caregivers described depletion of household resources due to medical expenses(17). In contrast, some South African studies suggest that social grants and pensions may partially offset financial burden, a support mechanism that is largely unavailable in Ethiopia(60).

The limited availability of such support mechanisms in Ethiopia may explain the heightened financial vulnerability observed in this study. Furthermore, the predominantly urban context of Addis Ababa likely exacerbates this burden, as caregivers struggled to balance formal employment and small-scale businesses with continuous caregiving, a challenge similarly reported among urban caregivers in Kenya(55).

6.5 Knowledge Gaps and Unmet Support Needs

The current study also revealed that caregivers frequently felt unprepared and unsupported in managing the complex needs of persons with dementia. Many participants reported limited guidance from healthcare providers, particularly regarding behavioral management, long-term care planning, and strategies for handling challenging situations at home. Caregivers explained that instructions were often restricted to basic medication administration, leaving them to rely on trial-and-error approaches to address day-to-day caregiving challenges.

This finding aligns with reports from other regions of Ethiopia, where mental health services predominantly focus on medication management with minimal caregiver education or counseling(75).

In the USA, Tanzania, caregivers similarly described reliance on trial-and-error caregiving due to limited professional guidance (55, 76). In contrast, pilot caregiver education initiatives in South Africa have demonstrated improved caregiver confidence and reduced distress, highlighting service inequities across countries(63).

The absence of home-based services, respite care, and structured caregiver training in Ethiopia—evidenced by the predominant focus of mental health services on medication management with minimal caregiver education or counseling—directly accounts for the heightened sense of unpreparedness and burden reported by participants in this study, unlike settings with pilot education initiatives that reduce distress. This disparity underscores the critical need for comprehensive national dementia plans in low- and middle-income countries like Ethiopia, which integrate psychosocial support and educational programs for caregivers, moving beyond purely pharmacological interventions.

6.6 Positive Outcomes, Resilience, and Coping Strategies

Despite extensive burden, caregivers described positive personal transformation, increased patience, emotional growth, and strengthened caregiver–patient bonds. Similar findings have been reported among caregivers in Ethiopia and Ghana, where caregiving is often framed as a moral, familial, and spiritual responsibility(32, 40, 60).

Spiritual coping, particularly prayer, emerged as a dominant strategy in this study and has been widely documented among caregivers in USA, Ethiopia, Nigeria, and Tanzania as a source of emotional regulation and resilience(49, 62, 71, 77). Family support, emotional sharing, acceptance, and self-motivation also functioned as protective factors, consistent with resilience-focused caregiving studies from Kenya(55) and South Africa(63).

These findings support resilience-based caregiving models that recognize caregiving as a dynamic process involving both suffering and growth.

6.7 Implications for Psychiatric Practice and Policy

The consistency of these findings with studies from China, Singapore, New Zealand, Japan, Ethiopia, Uganda, Tanzania, Nigeria, Ghana, Kenya, and South Africa underscores the need for caregiver-inclusive dementia care models. Psychiatric services at SPHMMC should incorporate routine assessment of caregiver burden, structured psychoeducation, and access to basic psychosocial support.

At the policy level, the findings support the development of dementia strategies that include caregiver training, stigma reduction initiatives, and financial protection mechanisms. Integrating caregiver support into primary healthcare and community-based mental health programs may offer feasible and culturally appropriate solutions.

These findings underscore the necessity of tailored interventions that consider both care duration and comorbidity complexity. For instance, long-term caregivers of patients with multiple chronic illnesses may benefit from targeted training, regular health monitoring, and respite care to prevent cumulative physical and emotional strain. Policies that integrate caregiver assessments into routine clinical practice could identify high-risk caregivers early and allocate support resources more effectively.

7. STRENGTH AND LIMITATION OF THE STUDY

7.1 Strength of the study

This study's main strength lies in its use of a qualitative phenomenological approach to generate rich, context-specific insights into the lived experiences of family caregivers of persons with dementia within a psychiatric care setting. Conducting the study at Saint Paul's Hospital Millennium Medical College enabled the inclusion of caregivers with diverse experiences and levels of caregiving responsibility. The use of in-depth interviews, data saturation, and systematic thematic analysis enhanced the credibility, depth, and rigor of the findings. The study also contributes valuable evidence to an under-researched area, with clear relevance for psychiatric practice and caregiver-inclusive dementia care in Ethiopia.

7.2 Limitation of the study

Several limitations should be acknowledged. First, the study was conducted at a single urban hospital, which may limit the transferability of findings to rural settings or caregivers without access to specialized services. Second, the small sample size and reliance on self-reported data may introduce selection, recall, and social desirability biases.

Additionally, the severity and stage of MNCD among care recipients were not systematically assessed. The hospital records did not consistently document dementia staging or severity classification, which limited the ability to explore how caregiver burden varied according to disease severity. Despite these limitations, the study provides meaningful and contextually grounded insights that can inform future research, clinical practice, and policy development.

8. CONCLUSION AND RECOMMENDATION

8.1 Conclusion

This study demonstrates that caregiving for persons living with dementia is a complex and demanding experience, characterized by substantial physical strain, emotional distress, social disruption, and financial challenges, all exacerbated by limited access to formal support services. Despite these burdens, caregivers exhibited remarkable resilience, a strong sense of moral responsibility, and reliance on spiritual and personal coping strategies that enabled them to sustain their caregiving roles.

8.2 Recommendation

Based on the findings of this study, the following recommendations are proposed for hospitals, healthcare providers, caregivers, community and religious leaders, civil society organizations, and future researchers.

For Saint Paul’s Hospital Millennium Medical College and Tertiary Health Institutions

- ✓ Develop structured caregiver education programs covering practical dementia care, behavioral management, and self-care strategies.
- ✓ Provide multidisciplinary support, including counseling, psychological assessment, and coordinated care plans, while linking caregivers to community resources.

For Mental Health Professionals

- ✓ Involve caregivers in care planning and provide culturally sensitive counseling addressing stress, grief, and caregiving challenges.
- ✓ Offer practical guidance on managing dementia-related behavioral and psychological symptoms, and encourage early help-seeking to prevent burnout.

For Community Leaders, Religious Institutions, and Civil Society Organizations

- ✓ Lead awareness campaigns to reduce stigma and misconceptions about dementia.
- ✓ Mobilize community and religious support structures to provide practical, emotional, and spiritual assistance to caregivers.

For families and caregivers

- ✓ Share caregiving responsibilities among family members and seek available health, counseling, and community support to reduce strain.
- ✓ Practice self-care, engage in coping strategies such as social and spiritual activities, and advocate for their own support needs.

To Future Researchers

- ✓ Further research is needed to better understand and quantitatively measure caregiver burden, explore the effectiveness of interventions, and examine caregiving experiences across diverse settings, stages of dementia, and caregiver characteristics.

Annex A: information sheet

Title of research project: The Lived Experiences and Burden of Caregivers of People with Dementia (MNCD): A Qualitative Exploration at Saint Paul's Hospital Millennium Medical College, Addis Ababa, Ethiopia, 2025 EC

Purpose of the study: The purpose of this study is to explore and describe the lived experiences, perceived burden, perceptions of dementia, and unmet needs of caregivers who provide care to individuals diagnosed with dementia at Saint Paul's Hospital Millennium Medical College in Addis Ababa, Ethiopia.

Procedures: Formal letter will be obtained from research and ethic committee of SPHMMC and informed consent will be obtained from each respondent just prior to the actual data collection. If you agree to this study, You will be asked open-ended questions about your experience in caregiving.

Risks: There are no known risks or discomforts associated with this study. Acceptance or refusal to participate will not affect the care provided.

Benefits: there will not be direct benefits to the participant. The results of the study will, however, assist the researcher in gaining a better understanding of lived experience of care givers of dementia patients.

Participant's rights: If the participant wants to withdraw from participating in the study, he/she can at any time.

Confidentiality: The information that is collected will be anonymous. However, I give my permission that information collected from me may be used for research and publication.

Principal investigator: Dr Michael Frew, MD, PYGIII

Tel: +2519202244413

Signature of participant Date.....

Signature of researcher..... Date.....

Annex B: consent form

Dear participants

My name is Michael Frew, and I am a 3rd year postgraduate resident in the Department of Psychiatry at SPHMMC.

Currently i am conducting a study on is to explore and describe the lived experiences, perceived burden, perceptions of dementia, and unmet needs of caregivers who provide care to individuals diagnosed with dementia at Saint Paul's Hospital Millennium Medical College in Addis Ababa, Ethiopia.

For your participation in this study, no payment will be granted. Besides, you're not obligated to answer any question which you do not wish to answer and you are free to withdraw at any point. The information that you gave will be kept confidentially and won't be accessed to a third party; only be used for the research purpose. If you are not going to be involved or withdrawn from the study, the right to get the service will not be compromised.

Thank you

Annex- C- Semi- structured questioner

Socio-demographic characteristics of the study participants

I) Personal Information

- Age _____ Occupation _____
- Sex _____ Educational status _____
- Marital Status _____
- Relationship to the person with dementia: _____
- Living arrangement with the patient: _____
- Duration of caregiving: _____
- The clinical severity of the dementia diagnosis , any medical comorbidity : _____

Describing the Day-to-Day Experience of Caregiving

1. Can you describe a typical day in your caregiving routine?

- What specific activities do you help your loved one with? For example:
 - bathing, dressing, eating, toileting, moving around, personal hygiene. preparing meals, managing medications, handling money, doing household chores, shopping, or transportation
- How much time do you spend each day?

2. How has your life changed since you became a caregiver?

Probes: In terms of your daily routine, plans, work, social, personal goals?

3. Do you get time for yourself? How do you usually spend it?

- Probe: Do you feel guilt, worry or relief when you're away?

4. Have there been any positive outcomes or rewards from caregiving?

- Probe: closer relationships, spiritual growth or satisfaction?

Exploring Caregiver Burden

1. How has caregiving impacted your emotional wellbeing?

- Probe: Feelings of sadness, stress, anger, guilt, helplessness, burnout

2. Have you noticed any physical health problems since you began caregiving?

- Probe: Fatigue, sleep issues, body pain , medical visits.

3. Has caregiving affected your relationship with others (e.g., spouse, siblings, children, friends)?

- Probe: Role strain, conflicts, or lost contact with anyone or received new kinds of support?
- 4. **What are the biggest challenges you face in caregiving?**
 - Probe: Patient behaviors (Agitation, restlessness, aggression, irritability, or shouting. Wandering, resisting care, or refusing to eat or take medication) managing finances, support from others.
- 5. **Have you ever felt overwhelmed to the point of thinking about quitting caregiving?**
 - Probe: What kept you going?

Exploring Caregivers' Perceptions of Dementia

1. **What do you believe is the cause of your loved one's condition?**
 - Probe: Medical, normal aging, something spiritual/cultural?
2. **What did you think or feel when you first learned the diagnosis?**
 - Probe: Denial, fear, confusion, acceptance.
3. **How do people in your community view dementia?**
 - Probe mental illness, part of aging, punishment
4. **Have you noticed changes in how your family or community treats your loved one?**
 - Probe: Supportive or discriminatory attitudes.
5. **Do you think dementia is curable or manageable?**

Probe: Expectations for recovery or decline.

Exploring Unmet Needs

1. **What kind of support do you currently receive (family, community, health professional help)?**
 - Probe: Emotional, financial, neighbors, church, NGOs, professional.
2. **What kind of support do you feel is missing or inadequate?**
 - Probe: training in caregiving skills, information, financial help, home care services dementia respite home, medication availability .
3. **If you had the power to change one thing about the care giving experience, what would it be?**
 - Probe: Policy, service access, public awareness.
4. **What suggestions would you give to healthcare professionals to better support caregivers like you?**

Additional Questions

1. **Is there anything else you want to share about your experience as a caregiver?**

አባሪህ፡ የመረጃ ቅፅ

የምርምር ፕሮጀክት ርዕስ፡ የዲመንሽክህ መምተን ከባቢዎች የሕይወት ተሞክሮ፡ በቅዱስ ጳውሎስ ሆስፒታል ሚሊኒየም ሜዲካል ኮሌጅ፣ አዲስ አበባ፣ ኢትዮጵያ፣ 2025 ዓ.ም.

የጥናቱ ዓላማ፡- የዚህ ጥናት ዓላማ በአዲስ አበባ ፣ ኢትዮጵያ በሚገኘው የቅዱስ ጳውሎስ ሆስፒታል ሚሊኒየም ሜዲካል ኮሌጅ በደመንሽክ ሕመም ለተያዙ ግለሰቦች እንክብካቤ የሚሰጡትን የሕይወት ተሞክሮዎችን፣ የንክብካቤ ጊዜ ቸገሮችን ፣ ያልተማሉ ፈላጎቶችንና የህመሙን ግንዛቤ ለመዳሰስ እና ለመግለፅ ነው።

ቅደምተከተሎች ፡ መደበኛ ደብዳቤ ከ SPHMMC የምርምር እና የሥነ ምግባር ኮሚቴ የተገኘ ሲሆን ከእያንዳንዱም ላሽሰጪ በመረጃ የተደገፈ የፈቃደኝነት መረጃ ይሰበሰባል ። በዚህ ጥናት ከተስማሙ፣ በመንከባከብ ላይ ስላሉት ልምድ ጥያቄዎች ይጠየቃሉ።

ስጋቶች፡ ከዚህ ጥናት ጋር የተያያዙ ምንም የሚታወቁ ስጋቶች የሉም። በጠናቱ መሳተፍ ወይም ለመሳተፍ ፈቃደኛ አለመሆን የሚሰጠውን እንክብካቤ አይጎዳውም።

ጥቅሞች፡ ለተሳታፊው ቀጥተኛ ጥቅሞች አይኖሩም። የጥናቱ ውጤት ተመራማሪው የዲመንሽክ ሕመምተኞችን ተንኮላቢዎችን በተመለከተ የተሻለ ግንዛቤ እንዲያገኝ ይረዳል።

የተሳታፊ መብቶች፡- ተሳታፊው በጥናቱ ከመሳተፍ ለመውጣት ከፈለገ በማንኛውም ጊዜ ይችላል።

ሚስጥራዊነት፡ የሚሰበሰበው መረጃ ምስጢራዊ ነው። የጠበቅ ይሆናል። ሆኖም ከእነዚህ የተሰበሰበ መረጃ ለጥናት ምርምር እና ለህትመት እንዲውል ፈቅጄያለሁ።

ዋና መርማሪ፡- ዶ/ር ሚካኤል ፍሬው፣ MD፣ PYGIII

ስልክ፡ +2519202244413

የተሳታፊ ፊርማ **ቀን**

የተመራማሪው ፊርማ
.....

አባሪ ለ፡ የፈቃድ ቅጽ

ውድተሳታፊዎች

ስሜዶ/ርሚካኤል ፍሬው እባላለሁ እና በSPHMMCየሳይካትሪ ዲፓርትመንት የ3ኛክመት የድህረምረቃፕሮግራምረዝደንትነኝ።

በአሁኑወቅትበአዲስአበባ፣ኢትዮጵያበሚገኘውየቅዱስጳውሎስሆስፒታልሚሊኒየምሜዲካልኮሌጅየዲመንሽክ ቸግርላለባቸውግለሰቦችእንክብካቤየሚያንከበካቤጊዜቸገሮቹን፣ያልተማሉፈላጎቶችናየህመሙንግነዛቤለመዳሰስ እናለመግለጽነው።

በዚህጥናትውስጥለመሳተፍምንምክፍያአይከፈልም፡፡ በተጨማሪም ፣መመለስየማትፈልገውን ማንኛውንም ጥያቄየመመለስ ግዴታ የለብህም እና በማንኛውም ጊዜ ለማቃረት ነፃነህ።

የሰጡትመረጃበሚስጥርይጠበቃልእናለሰስተኛወገንአይደርስም።ለምርምርዓላማብቻጥቅምላይይውላል።

በጥናቱ ውስጥ ካልተሳፉ አገልግሎቱን የማግኘት መብትየጠበቅ ነው።

አመሰግናለሁ

Amharic version questioner

1) የግል መረጃ

- ዕድሜ _____
- ስራ _____
- ጾታ _____
- የትምህርት ደረጃ _____
- የጋብቻ ሁኔታ _____
- ከታካሚ ጋር ያለ ግንኙነት: _____
- ከታካሚው ጋር የመኖርያ ሁኔታ: _____
- የእንክብካቤ ቆይታ: _____
- የመርሳት በሽታ ምርመራ ክሊኒካዊ ክብደት፣ ማንኛውም የሕክምና ተጓዳኝ በሽታ: _____

የዕለት ተዕለት የእንክብካቤ ልምድን መግለጽ

1. በእንክብካቤ ፕሮግራም ውስጥ የተለመደውን ቀን መግለጽ ይችላሉ?

- የሚወዱትን ሰው በምን ልዩ እንቅስቃሴዎች ይረዷቸዋል?

ለምሳሌ:- መታጠብ፣ ልብስ መልበስ፣ መመገብ፣ መጸዳጃ ቤት መሥራት፣ መንቀሳቀስ፣ የግል ንፅህና፣ ምግብ ማዘጋጀት፣ መድሃኒቶችን ማስተዳደር፣ ገንዘብ መያዝ፣ የቤት ውስጥ ሥራዎችን መሥራት፣ ግብይት ወይም መጓጓዣ

- በየቀኑ ምን ያህል ጊዜ ያሳልፋሉ?

2. ተንከባካቢ ከሆንክ በኋላ ህይወትህ እንዴት ተቀየረ?

- ምርመራዎች:- በዕለት ተዕለት እንቅስቃሴዎ፣ በእቅዶችዎ፣ በስራዎ፣ በማህበራዊ፣ በግል ግቦችዎ ረገድ?

3. ለራስዎ ጊዜ ያገኛሉ? ብዙውን ጊዜ እንዴት ያሳልፋሉ?

o ምርመራ:- በሽተኛውን በማይንከባከቡበት ጊዜ የጥፋተኝነት ስሜት፣ ጭንቀት ወይም እፎይታ ይሰማዎታል?

4. በመንከባከብ በኩል ምንም አዎንታዊ ውጤቶች ወይም ሽልማቶች አሉ?

- ምርመራ፡- የቅርብ ግንኙነቶች፣ መንፈሳዊ እድገት ወይም እርካታ?

የተንክብካቤን ተጽዕኖ ማለስ

1. እንክብካቤ በእርስዎ የአእምሮ ጤንነት ላይ ምን ተጽዕኖ አሳድሯል?

o ምርመራ፡ የመመርመሪያ ጥያቄዎች፣ የሀዘን ስሜት፣ ጭንቀት፣ ቁጣ፣ የጥፋተኝነት ስሜት፣ አቅመቢስነት፣

2. እንክብካቤ መስጠት ከጀመሩበት ጊዜ ጀምሮ ምንም አይነት የአካል ጤና ችግሮች አስተውለዋል?

o ምርመራ፡ ድካም፣ የእንቅልፍ ችግሮች፣ የሰውነት ህመም፣ የህክምና ጉብኝቶች፡፡

3. እንክብካቤ መስጠት ከሌሎች ጋር ባለዎት ግንኙነት ላይ ተጽዕኖ አሳድሯል (ለምሳሌ የትዳር ጓደኛ፣ እህትማማቾች፣ ልጆች፣ ጓደኞች)?

o ምርመራ፡ ሚና ውጥረት፣ ግጭቶች ወይም ከሌሎች ጋር ያለዎትን ግንኙነት ማጣት ወይም አዲስ ዓይነት ድጋፍ አግኝተዋል?

4. በእንክብካቤ ሰጪነት ውስጥ የሚያጋጥሙዎት ትልቁ ተግዳሮቶች ምንድናቸው?

• ምርመራ፡ የታካሚ ባህሪያት (ብስጭት፣ እረፍት ማጣት፣ ጠበኝነት፣ ብስጭት ወይም ጩኸት፡፡ መንከራተት፣ እንክብካቤን መቃወም ወይም ለመብላት ወይም መድሃኒት ለመውሰድ ፈቃደኛ አለመሆን) የገንዘብ ፣ የሌሎችን ድጋፍ፡፡

5. እንክብካቤ መስጠትን ለማቆም እስከማሰብ ድረስ ተጨንቀው ያውቃሉ?

o ምርመራ፡ በመንከባከብ እንድትቀጥል ያደረገህ ምንድን ነው?

የተንክብካቤዎችን ደመንሽያ ግንዛቤ ማለስ

1. የሚወዱት ሰው ሁኔታ መንስኤ ምን እንደሆነ ያምናሉ?

• ምርመራ፡ የሕክምና፣ መደበኛ እርጅና፣ መንፈሳዊ/ባህላዊ ነገር?

2. በሽታውን መጀመሪያ ስታውቅ ምን አሰብክ ወይም ተሰማህ?

o ምርመራ፡ መካድ፣ ፍርሃት፣ ግራ መጋባት፣ መቀበል፡፡

3. በማህበረሰብዎ ውስጥ ያሉ ሰዎች የመርሳት በሽታን እንዴት ይመለከቱታል?

• የአእምሮ ሕመምን፣ የእርጅና አካልን፣ መንፈሳዊ እምነቶች፣ የተሳሳቱ አመለካከቶች፡፡

4. ቤተሰብዎ ወይም ማህበረሰብዎ የሚወዱትን ሰው እንዴት እንደሚያዩ ላይ ለውጦችን አስተውለዋል?

o ምርመራ፡ ደጋፊ ወይም አድልዎ ያላቸው አመለካከቶች፡፡

5. የአእምሮ ማጣት ሊድን የሚችል ወይም ሊተዳደር የሚችል ይመስልዎታል?

ምርመራ፡ ለማገገም ወይም ለማሽቆልቆል የሚጠበቁ ነገሮች።

ያልተሟሉ ፍላጎቶችን ማሰስ

1. በአሁኑ ጊዜ ምን ዓይነት ድጋፍ እያገኙ ነው (የቤተሰብ፣ የማህበረሰብ፣ የጤና ባለሙያ እርዳታ)?

○ ምርመራ፡ ስሜታዊ፣ የገንዘብ፣ ጎረቤቶች፣ ቤተክርስቲያን፣ መንግስታዊ ያልሆኑ ድርጅቶች፣ ባለሙያ።

2. የጎደለ ወይም በቂ ያልሆነ ድጋፍ ምን ዓይነት እንደሆነ ይሰማዎታል?

○ ምርመራ፡ በእንክብካቤ ክህሎቶች፣ በመረጃ፣ በገንዘብ ድጋፍ፣ በቤት ውስጥ እንክብካቤ አገልግሎቶች ላይ ስልጠና፣ የመድኃኒት አቅርቦት

3. የመንከባከብ ልምድን በተመለከተ አንድ ነገር ለመለወጥ ኃይል ቢኖራችሁ ምን ይሆን?

○ ምርመራ፡ ፖሊሲ፣ የአገልግሎት ተደራሽነት፣ የህዝብ ግንዛቤ።

4. እንደ እርስዎ ያሉ ተንከባካቢዎችን በተሻለ ሁኔታ እንዲደግፉ ለጤና ባለሙያዎች ምን ዓይነት ምክሮችን ይሰጣሉ?

ተጨማሪ ጥያቄዎች

- ዲሚንሽያላለበት ሰው እንደተንከባካቢነት ስላለዎት ልምድ ማካፈል የሚፈልጉት ሌላ ነገር አለ?

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