"EXPLORING STRESS AND MENTAL HEALTH IN DEMENTIA CAREGIVER: A RESEARCH-BASED EVALUATION USING THE CAREGIVER SELF-ASSESSMENT QUESTIONNAIRE TOOL"

By

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A thesis submitted to the School of Pharmacy in partial fulfillment of the requirements for the degree of
Bachelor of Pharmacy (B. Pharm)

School of Pharmacy
BRAC University
February 2025

Declaration

It is hereby declared that

1. The thesis submitted is my/our own original work while completing degree at Brac University.
2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.
3. The thesis does not contain material which has been accepted, or submitted, for any other degree or diploma at a university or other institution.
4. I/We have acknowledged all main sources of help.

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Approval

The thesis/project titled ―Exploring stress and mental health in dementia caregiver: a research-based evaluation using the caregiver self-assessment questionnaire tool‖ submitted Upama Gope Puja (20346054), of Summer, 2024 has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Bachelor of Pharmacy on February,2025.

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Ethics Statement

This project does not involve any kind of animal and human trial.

Abstract/ Executive Summary

Dementia caregivers often experience significant mental health challenges due to the emotional and physical demands of caregiving. This research project explores the psychological well-being of caregivers using a Caregiver Self-Assessment Questionnaire, assessing stress, anxiety, depression, and overall burden. The study aims to identify key factors influencing caregiver mental health, including social support, coping strategies, and the severity of dementia-related behaviors. Findings indicate that high caregiving burden correlates with increased emotional distress, highlighting the need for targeted interventions such as counselling, respite care, and peer support groups. The results underscore the importance of early self-assessment in recognizing mental health risks and developing personalized coping mechanisms. By addressing caregiver stress proactively, healthcare providers can improve both caregiver and patient outcomes.

Keywords: Dementia caregivers, caregiver burden, self-assessment, respite care, support strategies.

Dedication

This research is dedicated to my beloved father, whose strength, wisdom, and unwavering support have been my greatest inspiration. His resilience and kindness have shaped my journey, motivating me to pursue knowledge and contribute meaningfully to this field. I am forever grateful for his love, guidance, and the values he has instilled in me.

Acknowledgement

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List of Acronyms

NINS&H	National Institute of Neuro Sciences & Hospital
ASB	Alzheimer society of Bangladesh
CGQ	Caregiver Questionnaire
AD	Alzheimer Diseases
WHO	World Health Organization

Glossary

Alzheimer‘s Disease**:** (AD)**:**		A progressive neurodegenerative disorder that affects memory, thinking, and behavior, and is a common cause of dementia.
Caregiver Burden	**:**	The physical, emotional, and financial strain experienced by individuals caring for someone with dementia.
CaregiverSelf-Assessment Questionnaire	**:**	A tool used to evaluate caregivers‘ stress levels, mental health status, and coping mechanisms.

Chapter 1

Introduction

1.1 Background

People over 65 are living longer and will likely be the fastest-growing group in the next few years. As people get older, they are more likely to get illnesses like dementia. Dementia is a neurological condition that causes people's minds to keep getting worse. Dementia is an illness that makes it hard for older people to do normal things. Because they are forgetting things, they need more help from family and friends. It is important for older people to have someone help them with their daily tasks. Caregivers of people with dementia have to deal with a lot of stress on an emotional, physical, and mental level. Research keeps showing that Caregivers are under a lot of stress, which can lead to mental health problems like sadness, anxiety, and tiredness. Studies have shown that long-term worry not only hurts the mental health of Caregivers but also damages cells and other body parts, which can make health problems worse over time (Anwar et al., 2017). Many individuals use the Caregivers Self-Assessment Questionnaire, which was made by the American Medical Association, to find out how stressed or depressed Caregivers are. This 18-item self-report test lets Caregivers figure out how stressed they are and how healthy they are in general. It has been shown to be useful for finding people who are likely to have major depression symptoms. The tool gives Caregivers useful information that makes them more likely to get medical help or support when they need it. The World Health Organization (WHO) says that around the world, 55 million people have dementia. Also, every year there are more than 10 million new cases. According to Hafiz et al. (2023), this disease affects mostly older people because it is the most common neurological condition in that age group. Based on these results, it is very important to deal with Caregivers stress in a comprehensive manner. Tools like the

Caregivers Self-Assessment Questionnaire are helpful for finding problems early and taking action, which leads to better results for both Caregivers and people with dementia.

1.2 Research gap

Dementia is an incurable disease. The global prevalence of dementia is rising, leading health services worldwide to focus on dementia care. The main care for dementia patients is provided by caregivers. An encouraging caregiver personality and a focus on the caring experience enhanced social support (Zhu et al., 2024). The well-being of caregivers is significantly affected by the responsibilities of their role; most caregivers indicate enduring stress, emotional distress, sadness, and an increased incidence of chronic illnesses. As a result, a fundamental aim of effective concern is to enhance the caregiver's mental health. The responsibilities of their role are already challenging for caregivers to navigate amidst their social, familial, career, and health concerns. The caregiver's mental health solution must be efficient, economical, and readily accessible. The digital tools for mental health that are available to support caregivers' mental health are examined in this scoping review (Petrovic & Gaggioli, 2020). This study aims to investigate the correlation between familial and mental health disorders, including anxiety, sadness, and stress while also conducting a comprehensive evaluation of dementia caregivers. To ensure those with dementia can live as long and well as possible, the caregiver's physical and mental health is essential and requires devotion. Web-based techniques can mitigate the adverse effects linked to caregiving by providing efficient and accessible help, alongside serving as an instructional resource. (Zhao et al.,2019). Also there is no such type of research yet which evaluate the stress level using this caregiver self-assessment questionnaire tool.

1.3 Objectives

The main objective of this research, to reflect on health, stress level and coping strategies of caregivers.

To use a self-assessment questionnaire to determine the financial, emotional, and physical strain that caregivers of dementia patients endure.

Also, to determine the main areas in which caregivers need more assistance, education, or resources in order to enhance both their own wellbeing and the standard of dementia care.

1.4 Significance

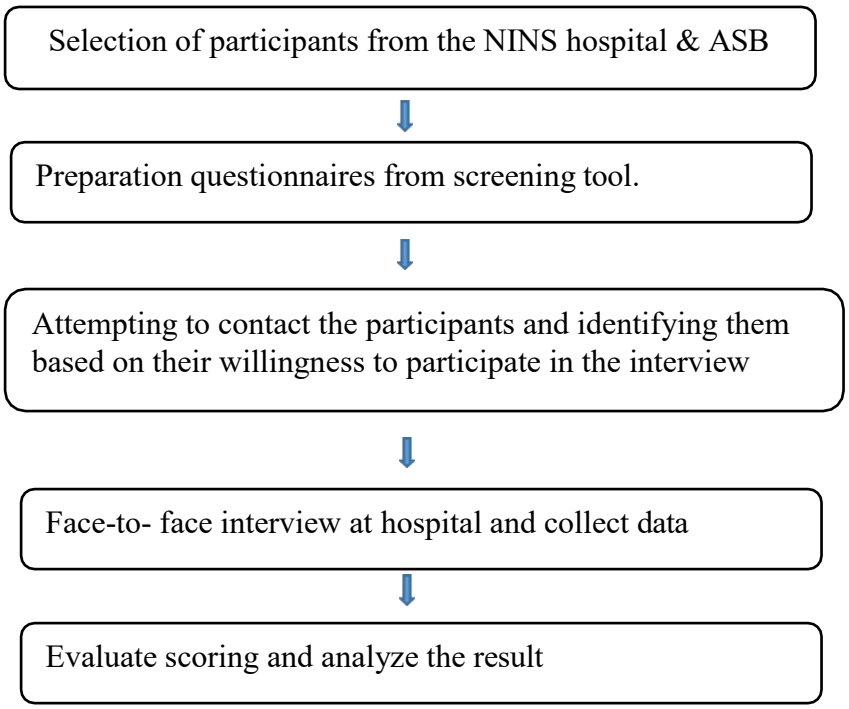
The main difficulties, like the patient's strange behaviors like wandering around during the day and at night, emotional reactions, and bad behavior, are the main things that cause cares of dementia to get stressed out and have health problems. Nonetheless, caregiver distress may also be affected by the specific form of dementia and the behavioral problems most closely associated with it. Increased caregiving intensity and diminished perceptions of support lead to greater struggles for dementia caregivers. It is noteworthy that caregivers of non-demented patients frequently encounter more stress owing to physical limitations, but caregivers of dementia patients seldom suffer from this issue. Delivering care can affect an individual's physical and mental health. Individuals from lower socioeconomic levels, women, and couples appear more at risk. Dementia caregivers exhibit diminished anxiety, self-efficacy, and subjective well-being, alongside elevated stress and increased symptoms of anxiety and depression compared to non-caregivers. They also have suboptimal physical health outcomes, including raised stress hormones, compromised immune systems, diminished antibody levels, increased medication consumption, and cognitive decline. Extra effort is required to identify the most vulnerable caregivers. These individuals often possess preexisting physical or mental health conditions. To identify caregivers who would benefit most from initiatives before the onset of clinically significant symptoms, tailored therapies necessitate comprehensive pre-intervention evaluation. The urgent need for screening instruments and procedures created and approved, especially for caregivers has been the subject of numerous studies (Sörensen & Conwell, 2011).

Chapter 2

Methodology

The experiences, difficulties, and requirements of caregivers of dementia patients are evaluated in this study using a survey-based design. The primary tool for collecting information will be a caregiver self-assessment questionnaire. The Alzheimer's Society of Bangladesh and the National Institute of Neuroscience Hospital (NINS) in Bangladesh are the sources of the caregivers' database. There were both men and women present, and all of the participants were older than 25. Family members and professional caregivers of dementia patients will be the study's main target.

- Flow chart describing the methodology of study :



2.1 Data Collection tool

The American Medical Association created an 18-item self-report questionnaire for caregiver to aid physicians in assessing the stress levels of whom accompanying patients with chronic illnesses to appointments. A series of statements, including "Over the past week or so, I have felt completely overwhelmed" and "Over the past week or so, I have felt strained between work and family responsibilities," are given to caregivers, who are asked to answer "Yes" or "No." Family caregivers can score their results and assess whether they are under a lot of stress using a straightforward scoring system. The scoring sheet that goes with it advises them to seek out caregiver support services and see a doctor for a check-up if they are experiencing a lot of stress.

Chapter 3

Result

This Caregiver self-assessment questionnaire has been tested among 50 dementia caregivers. Here 18 questions are given which is helping to determine the stress level of caregivers and it is showing along with pie chart.

First of all, the first question is from the 18 questions "Had trouble keeping my mind on what I was doing?" here 44% of responses are yes and 56% are no (Figure 1).

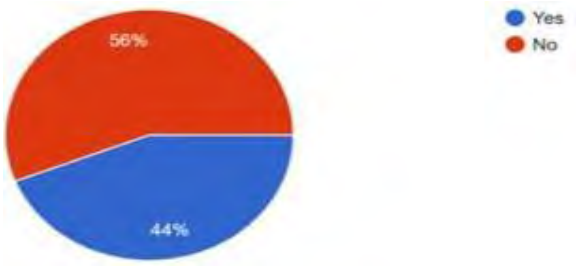


Figure 1: Pie chart for frequency percentage of the question ‘Had trouble keeping my mind on what I was doing?’

Secondly, for this question "Felt that I couldn't leave my relative alone." 84% of responses are yes and only 16% are no (Figure 2).

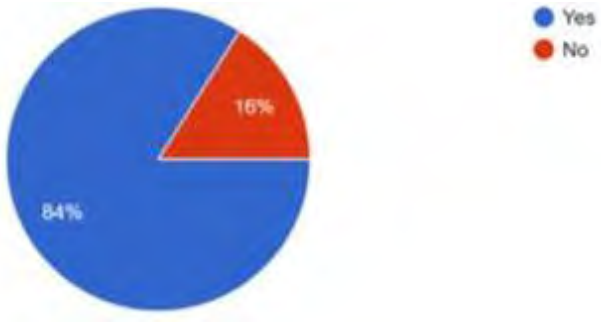


Figure 2: Pie chart for frequency percentage of the question “Felt that I couldn‘t leave my relative alone.”

Then the next one 38% are yes and the rest are no for the question "Had difficulty making decisions?" (Figure 3).

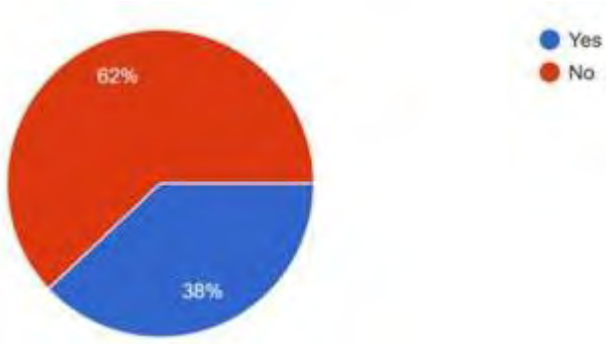


Figure 3: Pie chart for frequency percentage of the question _Had difficulty making decision?‘

Also for this question "Felt completely overwhelmed." The pie chart illustrates only 40% are yes and 60% are no (Figure 4). According to the caregiver self-evaluation questionnaire, the score for determining a high degree of distress, so here shows negative responses are much higher this is positive feedback for dementia caregivers.

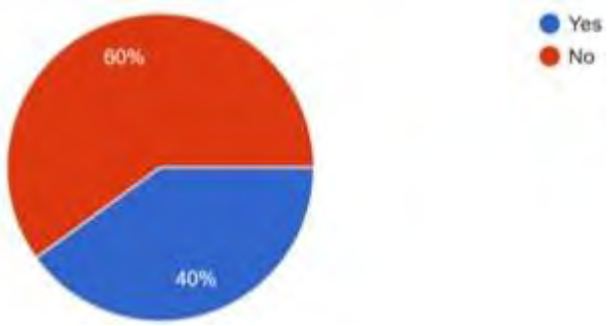


Figure 4: Pie chart for frequency percentage of the question _Felt completely overwhelmed‘

Besides through the question "Felt useful and needed" caregivers assessed their stress levels and here according to the self-evaluation criteria, this question was scored in reverse. According to self-evaluation, for determining the score this question response counted as a reverse score. So here felt useful and needed 84% of responses were — ‘yes’ but it counted as—‘No’ (Figure 5).

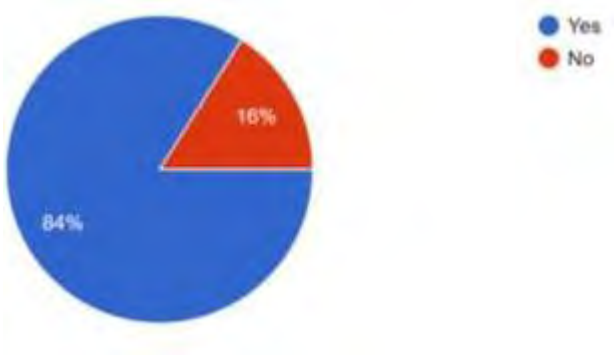


Figure 5: Pie chart for frequency percentage of the question ‘Felt useful and needed.’

Then there was only a 36% yes response for the "felt lonely" question and the rest are the no (Figure 6) which is a very good sign for caregiver's mental health.

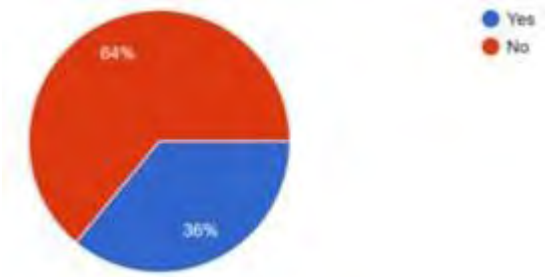


Figure 6: Pie chart for frequency percentage of the question _Felt lonely‘.

In response to the statement, "Been upset that my relative has changed so much from his/her former self," 82% of caregivers reported feeling this distress (Figure 7).

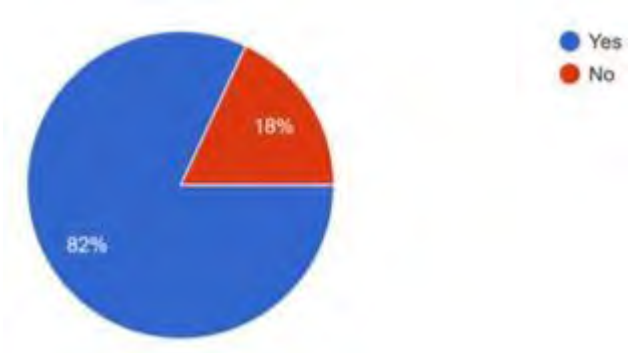


Figure 7: Pie chart for frequency percentage of the question _Been upset that my relative has changed so much from his/her former self.‘

Then for figure 8 & 9 questions "Felt a loss of privacy and/or personal time" (Figure 8) and "Been edgy or irritable" (Figure 9) there 50% of responses were yes and 50% were no.

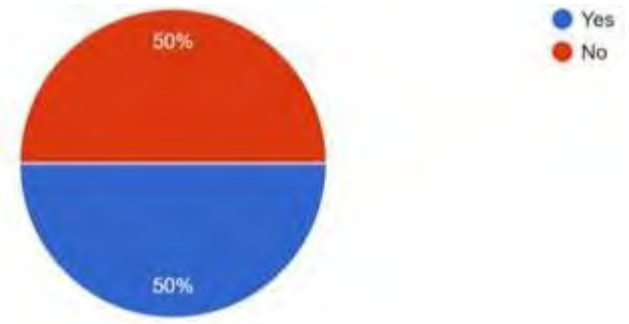


Figure 8: Pie chart for frequency percentage of the question _Felt a loss of privacy and/or personal time‘.

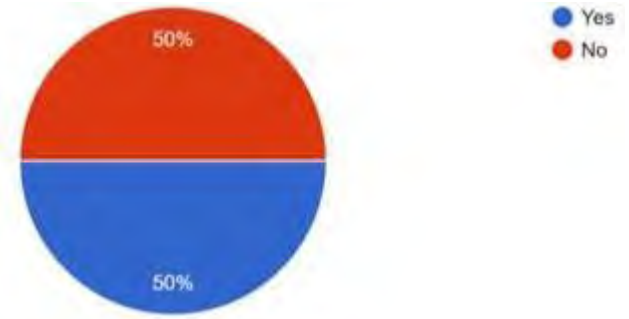


Figure 9: Pie chart for frequency percentage of the question _Been edgy or irritable.‘

In response to the statement, "Had sleep disturbed because of caring for my relative," 88% of caregivers reported experiencing sleep disruptions (Figure 10).

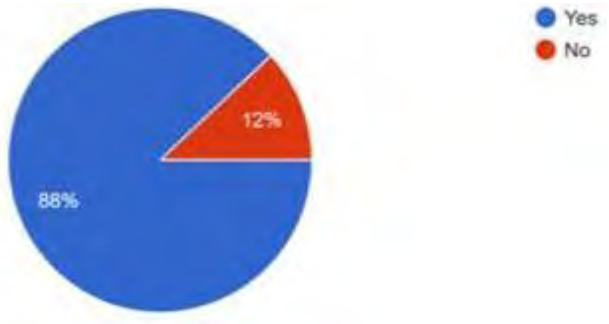


Figure 10: Pie chart for frequency percentage of the question ‘Had sleep disturbed because of caring for my relative.’

In response to the statement, "Had a crying spell(s)," 68% of caregivers reported "no," indicating that while caregiving is highly stressful, many may suppress their emotions or cope in different ways and only 32% say yes so there is less chance to experience high degree of distress (Figure 11).

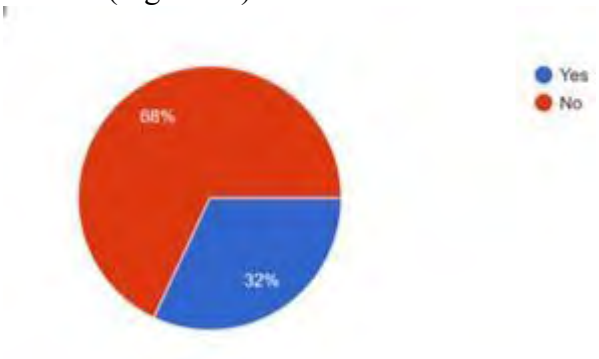


Figure 11: Pie chart for frequency percentage of the question _Had a crying spell(s).‘

In response to the statement, "Felt strained between work and family responsibilities," 74% of caregivers reported experiencing this conflict (Figure 12).

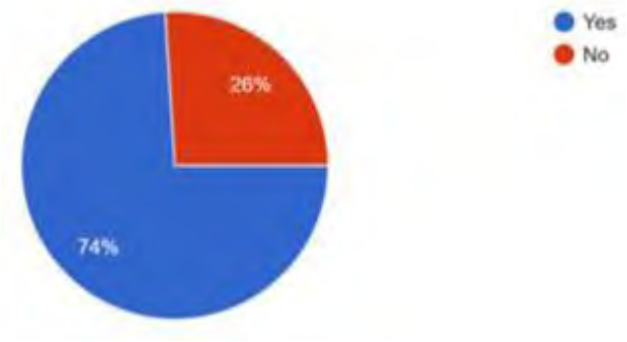


Figure 12: Pie chart for frequency percentage of the question _Felt strained between work and family responsibilities.‘

Additionally, 64% responded to having back pain (Figure 13).

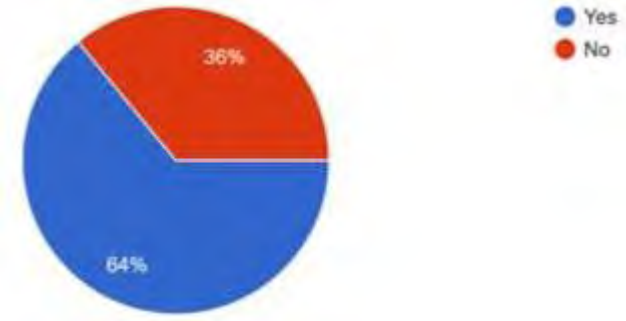


Figure 13: Pie chart for frequency percentage of the question _Had back pain.‘

Similarly for the question "Felt ill (headaches, stomach problems or common cold)" 60% responded yes and 40% said no (Figure 14).

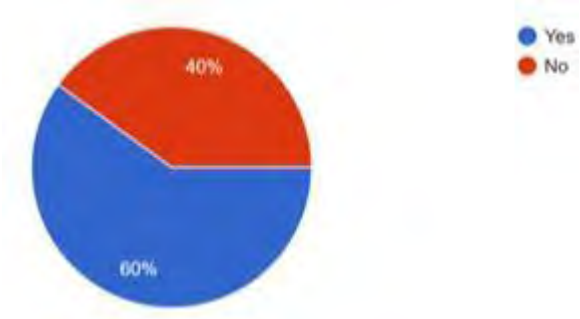


Figure 14: Pie chart for frequency percentage of the question _Felt it (headaches,stomach problems or common cold)‘

While in figure 15, 52% of caregivers reported not being satisfied with the support provided by their family, indicating a gap in assistance or understanding and figure 16, 46% found their relative's living situation to be inconvenient or a barrier to care.

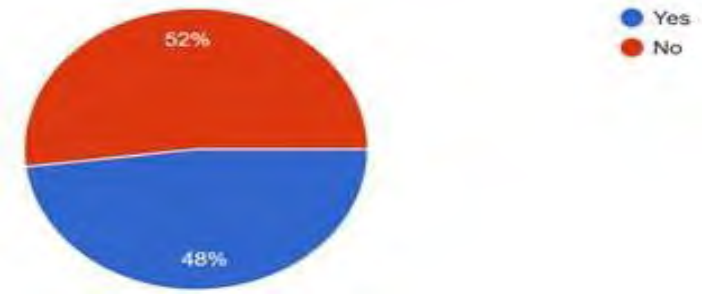


Figure 15: Pie chart for frequency percentage of the question ‘Been satisfied with the support my family has given me.’

Here also the same as 5 no question. This question response counted as a reverse score. So being satisfied with the support my family has given me, 52% of responses were ―yes‖ but it counted as ―No‖.

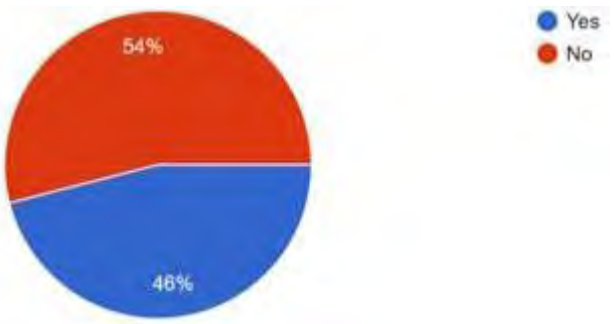


Figure 16: Pie chart for frequency percentage of the question _Found my relative‘s living situation to be inconvenient or a barrier to care‘.

The response to the stress level question, where the maximum rating was 7, indicates that while dementia caregivers experience considerable stress, it may not be at the highest extreme (Figure 17).

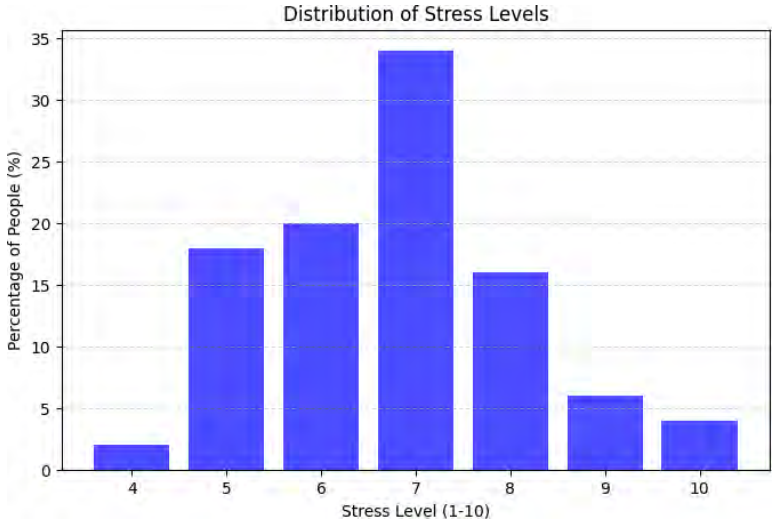


Figure 17: Bar diagram for frequency percentage of the question _On a scale of 1 to 10, with 1 being ―not stressful‖ to 10 being ―extremely stressful,‖ please rate your current level of stress.‘

Lastly, the responses to the health-related stress check question, with a maximum rating of 6 and a second rating of 8, suggest that dementia caregivers may be experiencing a decline in their health over the past year (Figure 18).

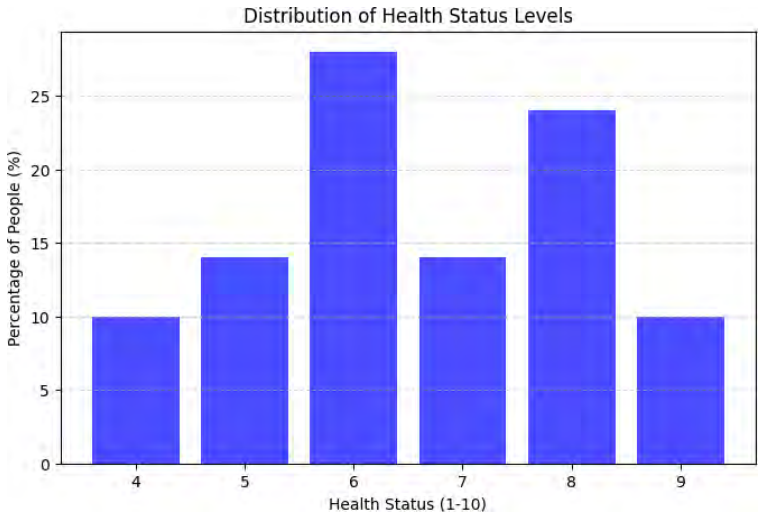


Figure 18: Bar diagram for frequency percentage of the question ‗On a scale of 1 to 10, with 1 being ―very healthy‖ to 10 being ―very ill,‖ please rate your current health compared to what is was this last year.'

According to the caregiver self-evaluation questionnaire to interpret the score of chances that are experiencing a high degree of distress:

- For question 4 (Felt completely overwhelmed) and 11 (Had a crying spell(s)) , if answer ―yes‖

  Here pie chart is showing, for question 4 ―yes‖ is 60% and 11 is 68%.

- If total ―yes‖ score is 10 or more than and here show score 7 ―yes‖. In addition, a score of 7 "yes" responses to the stress-checking questions suggests that the caregiver is likely experiencing a moderate degree of distress.
- If question 17 score is 6 or higher so here show maximum at 7 which has moderate to high stress risk.
- If question 18 score is 6 or higher so here show maximum at 6 which has moderate risk for illness.

Chapter 4

Discussion

In this study, a self-assessment questionnaire was utilized to evaluate dementia caregivers providing valuable insights into cognitive decline and caregiving challenges. Caregivers' responses highlighted the emotional, physical, and psychological burden associated with caregiving, emphasizing the need for adequate support systems. The findings suggest that such self-assessment tools are beneficial in raising awareness, facilitating early diagnosis, and guiding caregivers toward appropriate resources and coping strategies. In total 50 caregivers participated in the project to evaluate their stress levels. Here in the pie chart, the blue colored bar stands for yes and the red color is no. Additionally, one of the significant emotional challenges faced by dementia caregivers is witnessing the drastic changes in their loved one's personality and abilities. This high percentage highlights the profound emotional burden caregivers experience as they struggle to cope with the cognitive and behavioral transformations caused by dementia. Such changes can lead to feelings of grief, frustration, and helplessness, impacting caregivers' mental well-being. Moreover, sleep disturbances are a common challenge among dementia caregivers, often resulting from the constant need for vigilance and nighttime caregiving responsibilities. This high percentage reflects the significant physical and emotional strain associated with caregiving, as many caregivers must attend to their loved one's needs during the night, manage restlessness, or deal with unpredictable behaviors such as wandering. Chronic sleep deprivation can lead to increased stress, fatigue, and long-term health issues, further affecting caregivers' overall well-being. Also, the strain between work and family responsibilities is a common stressor for dementia caregivers. Then The responses to these stress-checking questions reflect some challenges faced by dementia caregivers. This suggests that not only is family support lacking for a significant portion of caregivers, but the physical environment may also hinder effective caregiving. Caregivers in this category may face overwhelming challenges related to their caregiving responsibilities, which can negatively impact their well-being. For the figure 17, a rating of 7 suggests that many caregivers are dealing with significant levels of pressure and emotional strain but may not be overwhelmed to the point of complete burnout. Therefore this highlights the ongoing challenges caregivers face, emphasizing the need for effective

support systems and stress management resources to help them cope with the demands of caregiving without reaching a crisis point. A rating of 6 for the question 18, indicates a moderate level of perceived health deterioration, while an 8 reflects a more significant decline, pointing to potential physical or mental health issues arising from the demands of caregiving. These findings underscore the importance of addressing caregivers' well-being, highlighting the need for proactive healthcare support, stress management resources, and interventions to prevent further deterioration in their health.

Australia and China both have many people with dementia and the number is expected to increase significantly by 2050. Basically, in 2005, there were 0.195 million people with dementia in Australia and 5.54 million in China, with projections showing these numbers will increase significantly by 2050 tripling in Australia and increasing fivefold in China. Most of these individuals depend on family caregivers, leading to a serious concern about caregiver burden, which affects the health of both the caregivers and care recipients. A study used Giddens' Structuration Theory and involved 148 caregivers 57 from Australia and 91 from China. The study found that care recipients in China needed more complex care and had more chronic illnesses than those in Australia, where there were more female and spousal caregivers. Most patients rely on family caregivers, leading to concerns about caregiver burden, which negatively affects both caregivers and those they care for. Well-designed social structures can help reduce this burden. Australia has established dementia services, but there is still room for improvement. In contrast, China, which has the highest number of dementia cases globally, lacks sufficient dementia services.

This article compares dementia caregivers in both countries to improve care. In Australia, caring for older people is seen as social welfare, leading to government support for caregivers. Yet, many families do not use available services. In China, care for the elderly is considered a family duty, with the government reinforcing this view, causing services to be underdeveloped. The role of family caregivers is declining due to societal changes, leading some families to hire paid caregivers when affordable (Xiao et al.,2014).

Chapter 5

Conclusion

This study explored the experiences of dementia caregivers, revealing the substantial effects of caregiving on their lives. The results of the research demonstrated the emotional, physical, and psychological difficulties that caregivers encounter, emphasizing the significance of efficient support systems. The study also highlighted the value of self-assessment tools in raising awareness, enabling early intervention, and directing caregivers toward appropriate coping mechanisms and resources. The research adds to the body of knowledge about dementia care and emphasizes how crucial it is to support caregivers to improve their well-being and the standard of care provided to dementia patients. The research looked at the experiences of 50 caregivers, and the findings showed a wide range of responses to the challenges of caregiving. The outcomes, which varied from caregiver to caregiver, shed light on the individualized character of the caregiving experience. The research also looked at how having access to community-based resources and support affected how well caregivers were doing. In conclusion, this study adds to the body of knowledge about dementia care and emphasizes how crucial it is to support caregivers to improve their well-being and the standard of care provided to dementia patients. It is crucial to recognize and address the particular difficulties experienced by caregivers, provide easily accessible community-based resources, and encourage the use of respite care.

5:1 Limitations

The results of this study might not be relevant to all dementia caregivers because of several limitations. The small sample size of 50 caregivers makes it difficult to extrapolate the results to larger groups. Future research should use bigger sample sizes and include more objective assessment techniques in order to produce more thorough and generalizable results.

5:2 Recommendations for Future Research

Future research should continue to examine the experiences of caregivers in order to create efficient treatments and policies that improve the lives of both caregivers and dementia patients. Also conduct studies with larger sample sizes and examine long-term impact of caregiving on mental and physical health.

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