

SOCIETY, STIGMA AND ALZHEIMER'S CARE GIVERS IN PIMS



HALLIMA SADIQ KAYANI
(MSC. ANTHROPOLOGY)

THESIS -2022

DEPARTMENT OF ANTHROPOLOGY
FACULTY OF SOCIAL SCIENCES
QUAID-E-AZAM UNIVERSITY
ISLAMABAD, PAKISTAN.

SOCIETY, STIGMA AND ALZHEIMER'S CARE GIVERS IN PIMS



*Thesis submitted to the department of Anthropology,
Quaid-e-Azam university Islamabad,
in the partial fulfillment of the master of science in
Anthropology*

by

HALLIMA SADIQ KAYANI

(MSC. ANTHROPOLOGY)

THESIS -2022

DEPARTMENT OF ANTHROPOLOGY

FACULTY OF SOCIAL SCIENCES

QUAID-E-AZAM UNIVERSITY

ISLAMABAD, PAKISTAN.

FORMAL DECLARATION

I therefore proclaim that I have delivered the present work independent from anyone else and with no guide other than those specified in this study. Any thoughts taken straight forwardly or in a roundabout way from outsider sources are demonstrated all things considered.

This work has not been distributed or submitted to some other examination board in the same or a comparative frame. I am exclusively in charge of this preposition, and I possess its sole copy rights Islamabad, 2022.

HALLIMA SADIQ KAYANI

ACCKNOWLEDGEMENT

In the name of Allah, the Merciful, the Beneficent. Praise be to the Lord of all worlds. Prayers and peace be upon our Prophet, Muhammad, his family and all of his companions. First and foremost, I want to thank Allah for letting me through all the difficulties. Without his support I would not be able to complete this thesis.

Secondly, I would like to acknowledge and give my warmest thanks to my respected supervisor **DR. IKRAM BADSHAH** who made this work possible. His guidance, healthy feedback and advice carried me through all the stages of writing my project.

I would like to thank DR. Aneela Sultana (In-Charge, Department of Anthropology) for her kind cooperation throughout the process of research. I also owe my gratitude to other faculty members DR. Anwaar Mohyuddin., DR. Inam Ullah Leghari, and DR. Rao Nadeem Alam for their encouragement.

I would also like to express my gratitude to my parents, who have always been there for me no matter what, and whose prayers have made it possible for me to complete my degree. Furthermore, I would want to thank my siblings, Usman Kiani and Siddiqa Kiani for their assistance and motivation during this degree whenever I needed it. Your prayer for me was what sustained me this far.

Furthermore, I would also like to express my sincerest gratitude to my friends Rabia Gohar, Zainab Hassan, Sana Fatima and Fiza Maheen for their love and support during my degree. Finally, I would like to thank all the respondents who have participated in the study's interviews.

HALLIMA SADIQ KAYANI

DEDICATION

This thesis is dedicated to my beloved parents and my siblings who have been source of inspiration and gave me strength when I thought of giving up, who continually provide their moral, spiritual, emotional and financial support.

To my supervisor, teachers and friends who shared their words of advice and encouragement to finish this study.

And lastly, I dedicate this thesis to almighty Allah, thank you for the guidance strength and power of mind.

ALLHAMDULILLAH

LIST OF TABLES AND FIGURES

LIST OF TABLES

| | |
|--|----|
| Table no 1: Departments of PIMS Hospital..... | 34 |
| Table no 2: Economic structure of the respondents..... | 40 |

LIST OF FIGURES

| | |
|---|----|
| Figure 1: Islamabad..... | 37 |
| Figure no 2: PIMS hospital..... | 41 |
| Figure no 3: OPD section of the PIMS hospital..... | 42 |
| Figure no 4: Institute of Alzheimer's Pakistan..... | 43 |

Contents

| | |
|---|-----------|
| ABSTRACT..... | 1 |
| CHAPTER 1..... | 2 |
| INTRODUCTION..... | 2 |
| RESEARCH PROBLEM..... | 4 |
| OBJECTIVES..... | 5 |
| SIGNIFICANCE OF THE STUDY..... | 5 |
| LIMITATIONS..... | 7 |
| CHAPTER 2..... | 8 |
| LITERATURE REVIEW..... | 8 |
| <i>ALZHMERS DISEASE</i> | 8 |
| <i>UNAWARENESS AND STIGMA</i> | 10 |
| <i>AGEISM</i> | 12 |
| <i>ECONOMIC IMPACT OF THE DISEASE</i> | 13 |
| <i>TREATMENT</i> | 13 |
| <i>CAREGIVING CONSEQUENCES</i> | 14 |
| <i>ALZHMERS IN PAKISTAN</i> | 16 |
| CHAPTER 3..... | 19 |
| METHODOLOGY..... | 19 |
| RESEARCH METHODOLOGY..... | 19 |
| RESEARCH APPROACH..... | 20 |
| QUALITATIVE METHODOLOGY..... | 20 |
| RESEARCH TECHNIQUES..... | 21 |
| PARTICIPANT OBSERVATION..... | 21 |
| KEY INFORMANT..... | 22 |
| RAPPORT BUILDING..... | 22 |
| PROBING..... | 23 |
| TOOLS FOR DATA COLLECTION..... | 24 |
| INTERVIEW GUIDE..... | 24 |
| <i>IN-DEPTH INTERVIEWS</i> | 24 |
| <i>FIELD NOTES</i> | 25 |
| <i>PHOTOGRAPHY</i> | 26 |
| SAMPLE AND SAMPLING TECHNIQUE..... | 26 |
| <i>DATA GATHERING</i> | 26 |
| DATA PRESENTATION..... | 27 |
| DATA ANALYSIS..... | 27 |
| <i>ETHICAL CONSIDERATION</i> | 28 |
| <i>INFORMED CONSENT</i> | 28 |
| <i>ANONYMITY AND CONFIDENTIALITY</i> | 29 |
| CHAPTER 4..... | 30 |
| AREA PROFILE..... | 30 |
| <i>LOCALE</i> | 30 |
| <i>HISTORY</i> | 31 |

| | |
|---|-----------|
| <i>LANGUAGE</i> | 31 |
| <i>CLIMATE</i> | 32 |
| <i>DEMOGRAPHY</i> | 32 |
| <i>RELIGION</i> | 33 |
| <i>EDUCATION</i> | 33 |
| <i>ECONOMY</i> | 33 |
| <i>HEALTH CARE</i> | 34 |
| <i>ENVIRONMENT</i> | 35 |
| DEMENTIA / ALZHEIMER’S DAY CARE CENTERS IN ISLAMABAD | 36 |
| CHAPTER 5 | 38 |
| COPING MECHANASIM OF FAMILY CARE GIVERS | 38 |
| INDIVIDUAL INTERVIEWS OF FAMILY CAREGIVERS..... | 41 |
| KNOWLEDGE AND AWARENESS | 42 |
| <i>PATHWAY TO DIAGNOSIS</i> | 42 |
| <i>UNDERSTANDING OF THE DISEASE</i> | 42 |
| STIGMA..... | 44 |
| <i>CASE STUDY</i> | 48 |
| <i>RELIGION</i> | 51 |
| <i>EXTERNAL HELP/CARE CENTERS</i> | 53 |
| <i>MISTRUST OF EXTERNAL SUPPORT</i> | 54 |
| <i>BARIERS</i> | 55 |
| <i>CASE STUDY</i> | 57 |
| CONSEQUENCES OF CAREGIVING..... | 59 |
| <i>CASE STUDY</i> | 60 |
| <i>CASE STUDY</i> | 62 |
| SUGGESTIONS ON HOW TO EDUCATE THE SOCIETY ABOUT THIS DISEASE..... | 63 |
| <i>ADDITIONAL FACILITIES AND STAFF</i> | 64 |
| CHAPTER 6 | 66 |
| GENERAL PUBLIC PERCEPTION OF THE DISEASE | 66 |
| KNOWLEDGE AND AWARENESS | 67 |
| BARRIERS IN RECIVIENG HEALTH CARE..... | 68 |
| RESPONSIBILITY | 70 |
| RELIGION | 71 |
| <i>SUGGESSTIONS</i> | 72 |
| CHAPTER 7 | 74 |
| SUMMARY AND CONCLUSIONS..... | 74 |
| <i>SUMMARY</i> | 74 |
| <i>CONCLUSION</i> | 75 |
| CHAPTER 8 | 76 |
| BIBLIOGRAPHY..... | 76 |

ABSTRACT

The topic selected for this research is society, stigma and Alzheimer's care givers in PIMS. In Pakistan, Alzheimer's research and services are scarce. There is limited information available in Pakistan on the prevalence and experience of Alzheimer's. In this regard this research has been conducted to assess people's understanding, beliefs, and attitudes concerning Alzheimer the following issues were investigated in the research were to document the perception of diversified segment of population about Alzheimer's disease, to document the various stigmas associated with Alzheimer, to compile coping mechanisms in family caregivers particularly and society in general. Semi-structured interviews were used to investigate the experiences of family caregivers of people with Alzheimer's and for the general public to investigate their understanding about Alzheimer's. The sample size was 15 caregivers and 20 respondents from general public. Caregivers and general public interviewed were aged 24–70. The interviews were done in Urdu initially, then translated into English and thematically evaluated. Knowledge and awareness; stigma; the significance of religion and the responsibility to care; the usage of day care centers and home-help; and barriers are some of the issues that arose from this study. Alzheimer's disease is widely misunderstood in Pakistan. Caregiving decisions were motivated by the religious obligation to care for one's family. Day care facilities and home-help services were poorly known, and they were frequently avoided and considered unfavorably. The novel results included caregivers thought that Alzheimer's/dementia should not be stigmatized, and that awareness should be promoted in Pakistan through TV, radio, and social media. More study is needed to evaluate attitudes about day care centers and home-help.

CHAPTER 1

INTRODUCTION

The population of the world is getting older at an increasing rate. People are living long and healthy lives as a result of improvements in the field of medicine throughout the previous century. However, this has led in a rise in the number of individuals suffering from non-communicable diseases such as Alzheimer's. Although Alzheimer's mostly affects the elderly, it is not an abnormal aspect of the ageing process. Alzheimer's is a condition caused by a number of brain disorders that affect memory, thinking, behavior, and capacity to conduct daily tasks. It is generally chronic or progressive disease and may be burdensome not just for the person suffering from it, but also for their caregivers and relatives. It is a significant source of disabilities and dependency among the elderly worldwide (Prince, WHO, 2012).

Alzheimer's is severely disabling not only for people who suffer from it but it is also distressing for their care givers and family. With Alzheimer's affecting an increasing number of individuals, practically everyone knows someone who has it or whose life has been impacted by it. The global population of individuals living with Alzheimer's is now estimated to be 35.6 million. This figure is expected to more than double by 2030 and more than triple by 2050 (Worthman, WHO, 2012).

The high global incidence of Alzheimer's, the economic effect on families, care givers, and communities, as well as the related stigma and social isolation, provide a huge public health concern. The international health community has acknowledged the need for action and has prioritized Alzheimer's on the public health agenda (Saxena, WHO,2012).

Most nations, including Pakistan, have some level of awareness and comprehension about Alzheimer's. Alzheimer's disease, which causes stigma, impediments to diagnosis and care, and physical, psychological, and economic repercussions on careers, families, and society, can no longer be neglected and should be put on the public health agendas of all countries (Zaidi, 2019).

Furthermore, the stigma associated with the diagnosis, as well as a lack of knowledge of dementia / Alzheimer's as a condition distinct from the normal ageing process, contributes to the difficulties in identification and management (Ferri, 2017).

The informal care burden is also expected to be larger in these low-resource nations like Pakistan, owing to the fact that round-the-clock care is required for persons with late stages of dementia, which leads to Alzheimer's disease (Balouch,2019).

Family members, mainly women, or unskilled informal caregivers are on the front lines of Alzheimer's care in the home. This frequently puts a tremendous strain on families and may have poor health, social, and economic consequences (Chaudary,2019).

In nations such as Pakistan, there is also a scarcity of social science research. In Pakistan, nothing is known about the prevalence and experience of dementia. The 10/66 research project conducted population-based dementia/Alzheimer research in low- and middle-income nations, although Pakistan was not one of its research locations (Willis.2019).

Pakistan ranked very poorly in terms of elderly health, with a somewhat low life duration and even lower healthy life span within the region (Zaidi,2016).

Despite the increased number of older people in Pakistan, as well as their poor socioeconomic condition, there has been relatively little study on issues related to old age, particularly the growing public health concern of Alzheimer's and dementia (Zaidi, 2019).

Alzheimer has a huge influence on the life of the family, especially the one who is in charge of providing care. The bulk of care is provided by family and other informal community support organizations, and women comprise the majority of caregivers. Caregiving for someone with Alzheimer's can put a significant strain on those who do the majority of the work. Physical, emotional, and financial concerns are all present.

Despite the fact that services are available in certain parts of Pakistan, there exist impediments to adoption. Service use is hampered by a lack of knowledge of resources, a lack of understanding or stigma linked to the condition, past unsatisfactory experiences with services, and cultural, linguistic, and financial hurdles. Education and awareness campaigns targeting the general population, including people with Alzheimer's, their care givers, and families, can promote service

utilization by making people aware, enhancing understanding, and diminishing stigmatizing attitudes.

Support is required to allow informal caregivers to remain in their roles for as long as possible. Information to enhance comprehension, skills to assist in caring, respite to allow participation in other activities, and financial support all are kinds of support.

To advocate for the most effective policies and programs in increasing awareness and giving formal assistance to individuals with Alzheimer's and their care givers to lessen their burden and stress, research must be conducted to assess people's understanding, beliefs, and attitudes concerning Alzheimer. In this regard the current study intends to investigate the cultural beliefs, attitudes, opinions, and understanding of Alzheimer's and its care, among Alzheimer's caregivers and the general public. This study will also look into the problems that caregivers encounter as well as the stigmas linked with this disease.

RESEARCH PROBLEM

There is a general culture in Pakistan that we always attach a stigma with mental health and that is why we avoid it from the general public and we avoid to discuss publicly and that is the basic reason that when you cannot acknowledge dementia/ Alzheimer's as a disease how come you can work for the treatment of the disease. Not only it is a medical disease that is going to influence the physical and mental health of the affected person but at the same time this disease can also have an adverse impact on the life of the socially related people. So, this lack of knowledge and understanding of dementia/Alzheimer's in Pakistan, leading in stigma, impediments to diagnosis and care, and, most critically, a physical, psychological, and economic effect on caregivers, families, and societies. The study examines the general public's awareness of Alzheimer's disease and its treatment in Pakistan. There were stigmatizing opinions toward Alzheimer's disease in the public, which evolved mostly as a result of unfavorable and incorrect conceptions regarding dementia's causes. Alzheimer's disease is usually thought by the caregivers to occur as a natural part of the ageing process, as a result of stressful events, stress, anger, overthinking or physical weakness etc. in Pakistan. Most importantly the Alzheimer's disease has a significant influence on the life of the family, particularly the primary caregiver and majority of care is supplied by family

and other informal community support structures, and through this study I have analyzed that the most of caregivers are women primarily wife's, daughters and daughter in laws.

In terms of disability and care requirements, Alzheimer's disease is one of the most severe lengthy disease conditions. Caring for an Alzheimer's patient may put a significant strain on them as this disease necessitates the patient's long-term care. The phrase "long-term care" refers to a wide range of services that assist persons who are unable to care for themselves due to a chronic condition or disability in meeting their medical and nonmedical needs. This study looks into the effects of caring on family members, namely the primary caregiver. The vital job of family caregivers is frequently unappreciated and neglected. Because the disease progresses slowly, family members usually provide care for many years and are under a lot of stress for long periods of time. The chronic exhaustion caused by providing long hours of care without breaks exacerbates the effects of elevated stress levels. Physical, mental, and financial stress are among the stresses that the care givers go through while taking care of the patient. In addition, this study also examined the views of care givers, family members and general public about the day care centers present in the society. In Pakistan, there are essentially no good public health centers or specialized day care centers for the elderly, and there is no government strategy in place to help those living with Alzheimer's disease.

OBJECTIVES

The main objectives of the research are,

- To document the perception of diversified segment of population about Alzheimer's disease,
- To document the various stigmas associated with Alzheimer.
- To compile coping mechanisms in family caregivers particularly and society in general.

SIGNIFICANCE OF THE STUDY

This research analyzes the experiences of care givers of Alzheimer's patients in PIMS. It also analyzes the understanding of the general public about Alzheimer's disease and its care. The purpose of this research is to make people aware about this disease as most of the people interviewed were unaware of the disease and those who knew about this disease were still lacking in their knowledge about it.

The public's impression of Alzheimer's is greatly impacted by a lack of knowledge about the disease. This study will also help in reducing stigmatizing attitude of the society toward this disease by increasing the awareness of the society. Secondly the study also aims to help government make policies regarding this disease as in our society there are very few facilities available to the people. The patients as well as the care givers have to suffer because of that. there are no day Care Center's specific for Alzheimer's and also no hospital specifically for Alzheimer's patients.

In Pakistan the public health resources are so scarce and because of that the burden of informal care is very high moreover the disease is a progressive and long-term care is required. There is also scarcity of significant social science research in Pakistan, particularly in Rawalpindi/Islamabad, and more work must be done to assess people's knowledge, views, and opinions towards Alzheimer in order to advocate for the most beneficial plans and practices for promoting awareness and providing support services to individuals with Alzheimer's and their caregivers The present study intends to fill this gap. Major Policy Suggestions resulting from this Study Includes.

- Creating a nationwide campaign to improve Alzheimer awareness, identifying symptoms and their progression, as well as how to seek support and get a diagnosis.
- Creating a national effort to promote awareness of day care facilities for Alzheimer's patients in order to assist and support caregivers in lowering the strain of long-term care while also educating them on appropriate patient care.
- Experts, religious leaders, and community leaders must use an effective awareness approach to promote awareness and increase the acceptability of receiving aid from sources other than home.
- The government should create Alzheimer/dementia-specific hospital and day care centers in twin cities, and health care providers should be highly trained for diagnosis and management.

Pakistan has a scarcity of research and evidence-based policymaking so, there is a need in Pakistan to upgrade and expand Alzheimer's and related dementia research. While this work gives unique insights into the lives of Alzheimer's patients and care givers in Islamabad, Pakistan's most prominent city, it is far from a representative sample of all individuals living in Pakistan. There is an urgent need to determine if these findings are consistent with those found in rural areas of Pakistan, where healthcare services are more widely dispersed, poverty is higher, and religious views may be more diverse. In addition, nationally representative research of Pakistanis might aid in determining if certain demographics or cultures influence attitudes and awareness about Alzheimer. This will increase our grasp of Alzheimer awareness and practices in Pakistan

LIMITATIONS

Present study is very significant and completed in itself and it fills major lacuna in the literature giving satisfied answer to the research questions and thus fulfilling the objectives of the study still, there are limitations in this study which are:

- First and most obvious was that the Alzheimer's patients are not registered in the hospitals as there is no specific hospital for Alzheimer's and also in other hospitals so that is why the sample size of my research is small.
- Secondly the data was gathered from only one hospital of Islamabad so the study doesn't extend to all the hospitals of Islamabad. Most of the patient didn't allow to visit their home and do recording and most of them didn't have much time for the interview.
- Furthermore, the research is more specific in nature as it only focuses on the caregivers, the general public views on the disease and views of the care centers so the other aspects like it doesn't focus on the disease or the patient.
- Lastly the study only uses qualitative methodology.

CHAPTER 2

LITERATURE REVIEW

ALZHEIMERS DISEASE

As per the ADI World Report 2016, more than 47 million individuals globally have Alzheimer, with the figure anticipated to increase to even more than 131 million by 2050 (Alzheimer's Disease International, 2016).

According to NIA, Alzheimer's disease is a brain disease that gradually deteriorates memory and cognitive abilities, as well as the capacity to do even the most basic duties. Most persons with the condition those with late-onset symptoms have symptoms in their mid-60s. Early-onset Alzheimer's disease is extremely uncommon and occurs between the ages of 30 and 60. Alzheimer's disease is the leading cause of dementia in older people (National Institute Aging, 2021).

Alzheimer's disease is the most common dementing disorder in older persons, affecting approximately 7–10% of the individuals over the age of 65 and up to 40% of persons over the age of 80 (Ecklund, Torres, 2005) The characteristics of Alzheimer's disease and other forms of dementia differ, although there are many commonalities. Memory loss and a decline in practical ability are the most prevalent early indicators of Alzheimer's, which can lead to withdrawal from work or social activities. Every individual is different, and Alzheimer differs from person to person. no two individuals will develop characteristics of the disease in the same way. The personality, overall health, and personal status of an individual all have a role in defining the effect of Alzheimer upon him and her (National Institute of Aging).

According to studies on Alzheimer's disease, it is a brain ailment that slowly depletes memory and brain functions, as well as the ability to do even the most basic activities. Alzheimer has affected 47 million people worldwide, and this statistic is anticipated to rise in the coming years. The signs of Alzheimer's disease vary from patient to patient. Memory loss, trouble doing everyday duties, difficulties with speaking, writing, and conversation, and confusion in time and location, Poor or diminished judgement, Attention, planning, or organization issues, Misplacing items, Emotional or behavioral changes, difficulties with pictures or physical connections, and withdrawal from work or socializing activities.

Alzheimer's is severely disabling not only for people who suffer from it but it is also distressing for their care givers and family. With Alzheimer's affecting an increasing number of individuals, practically everyone knows someone who has it or whose life has been impacted by it. The global population of individuals living with Alzheimer's is now estimated to be 35.6 million. This figure is expected to more than double by 2030 and more than triple by 2050. The different healthcare demands of the huge and quickly expanding population of vulnerable and dependent older people should be of serious importance to authorities in all nations. This is especially true for Low- and Middle-Income Countries, which will have the highest growth in ageing over the next few decades. This calls on governments to create and enhance services for individuals with Alzheimer, with an emphasis on early treatment, supportive environments, and a flexible health and social care system. To meet the growing requirements of persons with Alzheimer's and their caregivers, comprehensive and unified health and social systems and services will be essential. Such approaches should ensure that the requirements of minority demographic groups are addressed. Peak incidence occurs in Europe and the Americas among those aged 80–89 years, in Asia amongst aged 75–84 years, and in Africa among those aged 70–79 years. According to the researchers, almost 7.7 million new instances of Alzheimer's are diagnosed globally every year, meaning one new case every 4 seconds (World Health Organization, 2012).

"...Alzheimer's disease affects a growing number of our country's elderly and their families, and it is critical that we address the threat it poses to healthcare system..."Barack Obama, President of the United States of America, in 2011.

Alzheimer's disease doesn't only affect the person only but also his family members and all those people who are related to him. So not only the patient suffers from this disease but also his family member who provide him care. Though understanding of Alzheimer as a public health concern is growing in certain high-income nations, Alzheimer has been missing or low on the health agenda of Lower Middle-income countries, and has received scant attention in global health initiatives. This is ignoring the significant global prevalence of dementia, its financial burden on families, care givers, and societies, as well as the accompanying stigma and social marginalization. The World Health Organization (WHO) estimates that around 25% of the worldwide people struggles from a mental or behavioral problem at a certain time in their lives. This emotional and behavioral health issue is expected to account for 12% of the global illness burden, with that figure likely to increase to 15% by 2020 (Hugo, 2003) Mental and behavioral health issues impact around 57

million people in the United States (National Institute of Mental Health, 2006). Despite the high prevalence of these disorders, known treatments were seen to be capable of lowering reducing pain and improving functional capacity.

UNAWARENESS AND STIGMA

Different sections of the globe regard Alzheimer's disease symptoms differently. This includes viewing Alzheimer's disease as a natural part of ageing, mental illness, and metaphysical or irreversible brain ailments tied to paranormal or spiritual beliefs. It is vital to enhance public knowledge and understanding of Alzheimer in order to reduce the stigma attached with it. This can only be done by well-conceived and implemented political and public efforts to aid society's shift toward acceptance and inclusion of persons with Alzheimer. Uncertainty about Alzheimer's disease can lead to a number of misconceptions, which can contribute to stigma, which is common at all levels in most countries. In his basic definition, Goffman (1963) defines stigma as "a highly invalidating attribute" and posits that the afflicted person is converted "from a full and ordinary person to a tainted, dismissed one". He defines stigma as "a unique link between a trait and a stereotype." Stigma, according to Goffman, arises from a disparity between "virtual social identity" (how an individual is seen by society) and "real social personality" (the characteristics that a person genuinely possesses) (Yang, 2007).

Mental illness is used as a framework for humor in movies and television, with spectators laughing at rather than with the characters. As part of the 'them and us' perspective, mental illnesses have also been linked to highly loaded negative personality traits, providing a justification for carelessness and crime (Bryne,1997) Hyler et al (1991) have commented about a variety of Films in which mental disorder is portrayed as "overly entitled, immoral narcissistic parasites."

Over a ten-year period, there was no change in two similar UK public opinion surveys, with more than 80% agreeing that "most people are embarrassed by mentally ill people," and roughly 30% admitting that "I am embarrassed by mentally ill individuals"(Huxely,1993).

The social illegitimacy of the mentally sick is exacerbated by the public stigma associated with psychiatric diseases. They are viewed as incapable of regular contact, harmful, and unreliable, and as a result, they are excluded from the society. Because of their illegitimacy, the stigmatized are no longer protected by a number of implicit social standards that regulate all interactions. The

chaotic influence of stigma is determined by how it is classified along multiple dimensions: accessibility, omnipresence, precision, significance, applicability, sensitivity, learning accountability, and removability (Elliott,1982).

Neuropsychiatric diseases are projected to account for 11.9 percent of the total disease burden in Pakistan. In impoverished nations, less than 35% of mental patients obtain treatment. Individuals frequently do not seek basic treatment owing to their fear of public stigma and humiliation, despite the availability of (though limited) mental care (Waqas,2014). Failing to address negative stereotypes and its consequences can lead to the social isolation of individuals with mental illnesses.

A study was undertaken in Pakistan on medical and non-medical students to ascertain their perspectives on the causes of mental disease. medical students were more likely to identify psychosocial trauma, work-related stress, genetic susceptibility to mental diseases, physical violence, study-related pressure, and divorce as risk factors for depression non-medical students, on the other hand, were more likely to cite the evil eye, God's wrath, and Jinn (demons) possession as conceivable causes of mental diseases. Medical students, on the other hand, exhibited more favorable attitudes about persons with mental illnesses than students enrolled in nonmedical academic areas. Students who'd already read books on the topic, looked for or chatted with persons suffering from mental illnesses were less authoritarian and less socially restricting, more sympathetic, and had a more positive community perspective. In Pakistani medical institutions, behavioral sciences are taught as part of the undergraduate curriculum. As a result, most medical students in that survey already knew more about mental diseases than students from other specialties. This study was conducted by (waqas,2014) and his colleagues on the topic public stigma associated with mental illness in Pakistani university students.

According to another research (Gureje,2005) on the topic public study of awareness and perspective about mental disorder in Nigeria, the majority of respondents felt that substance usage (liquor or drugs, especially drugs) may lead to psychiatric condition. The concept that mental disease is caused by demonic spirits was the second most generally supported etiology of mental illness. Following that, trauma, stress, and genetics were all mentioned as probable reasons. Only around one-tenth of those surveyed felt that biological issues or brain damage were the root causes of cognitive illness. Over 9 percent felt mental disorder may be caused by God's retribution,

whereas only roughly 6 percent thought unemployment could cause mental disease, confirming a larger belief in supernatural explanation.

People with Alzheimer's disease are commonly secluded or concealed due to the obvious stress associated with the condition and the possibility of adverse reactions from Neighbors and family to social and cognitive indications. The knowledge that you have no way of assisting someone with Alzheimer's disease might bring sadness and melancholy. Immediate effort is essential to raise Alzheimer's education and reduce stigma. To that purpose, ADI has issued a stigma journal article to correspond with World Alzheimer's Month 2012.

AGEISM

Ageism is a type of prejudice that is based on "stigmatizing and extrapolating about person involved on their ages" (Barker, 1995) It depicts ageing as an unavoidable degradation, leading in uselessness and incapacity to be productive (Laws, 1995). The widespread assumption that most elderly persons are mentally incapacitated echoes the traditional concept of ageing as a path to incompetence and forgetfulness (Gatz & Pearson, 1988).

Due to a major lack of information, individuals believe that Alzheimer's is a natural part of the ageing process, and that ageing causes mental impairment. Alzheimer's is not a natural part of the ageing process, and it does not affect every elderly person.

Ageist views may be found in a variety of cultural situations. African-American culture has recorded the belief that Alzheimer's disease manifestations are a normal part of aging (Ballard, Nash, Raiford, & Harrell, 1993).

Regardless of how popular these ageist beliefs are, there is no evidence that considerable memory loss is unavoidable in old age (Kaplan & Sadock, 1998; Schneck, Reisberg, & Ferris, 1982). However, society perceives its elders as being prone to disorientation and cognitive decline.

While certain Alzheimer symptoms, such as memory loss were thought to be part of the natural process of aging, some South Asian caregivers saw Alzheimer as demons or God's retribution. According to the majority of research, many South Asians explicitly associate negative stereotypes with Alzheimer's (Hossain, 2020).

ECONOMIC IMPACT OF THE DISEASE

A thorough understanding of the expenses of Alzheimer's disease, as well as how they affect family members, authorities, as well as their different healthcare infrastructures, is critical for making people aware, accomplishing proper consideration, and putting more emphasis on efforts to make people's lives better with Alzheimer's and their caregivers. Expense analyses for Alzheimer have been conducted in a few, mostly high-income nations, including Australia, Canada, Sweden, the United Kingdom, and the United States, as well as the European Union. The general opinion is that Alzheimer is already causing serious economic burdens, both directly (health and psychosocial care) and indirectly (unpaid caregiving by families and friends). Evidence of the magnitude of the economic impact in middle-income nations is now emerging.

Care contributions from family members, friends, and others have a significant impact on the social expenses of Alzheimer. The base option was the sum of basic daily living activities (Activity of daily living, such as eating, dressing, bathing, toileting, and grooming) and instrumental daily living activities (Instrumental activities of daily living, such as shopping, preparing food, utilizing transportation, and managing personal money).resources for care. The global social financial cost of Alzheimer is US\$ 604 billion, with elevated countries bearing 89 percent of the burden (Castro, 2010).

TREATMENT

There is currently no totally accurate or efficient clinical treatment for Alzheimer's disease; nevertheless, there is evidence that organized support networks can help persons living with Alzheimer's disease improve the lives of people (Downs and Bowers, 2010). Alzheimer knows no limits, whether they societal, financial, or cultural. There is no cure for Alzheimer 's disease at the moment, but there is a wide range of assistance available for individuals with dementia / Alzheimer's and their caregivers. Around the world, up to three-quarters of those suffering with Alzheimer have not been diagnosed. Almost 80% of the overall population is afraid of having dementia at some time, and one-quarter believes there is hardly anything we can do to prevent Alzheimer. Almost 62 percent of health professionals globally falsely believe that Alzheimer is a natural component of ageing. Around the world, 35% of caregivers stated they have concealed a

family member's Alzheimer diagnosis. While there is currently no treatment for Alzheimer's disease or most other types of dementia, the symptoms of Alzheimer's disease, such as restlessness and sadness, can be addressed. Medication may also be used to improve someone's memory, particularly in the early stages of dementia. It is also feasible to assist persons suffering with dementia and their caregivers in a number of practical ways. These are methods of caring for persons with dementia /Alzheimer's that capitalize on those affecter's talents and abilities. This enables that person suffering from dementia / Alzheimer's retain a feeling of well-being and uniqueness during their disease (Alzheimer's Disease International).

CAREGIVING CONSCEQUENCES

Caregiving is defined by Shulz (2004) as "... the supply of exceptional care, beyond the confines of what is normal or typical in familial relationships." Caregiving often entails a large investment of time, effort, and finances over relatively extended durations; it entails chores that may be undesirable and uncomfortable, as well as emotionally and physically challenging. "According to Alzheimer's disease international Over half of all caregivers worldwide report that their health had also affected as a consequence of their caring obligations, despite having favorable feelings about their role.

Japan, which has the world's highest incidence of ageing, launched a public long-term care insurance scheme in April 2000. The insurance intends to: assist those in need of long-term treatment; determine the association between costs and benefits by introducing a national insurance approach; enable health service users to obtain wide range of services from a wide range of accommodations of their choice; and distinct long-term care from health care insurance coverage. The problems for policymakers around the globe in managing to the rising number of Alzheimer's patients are significant. To enhance the care which includes experiences of persons with dementia and family caregivers, a public health strategy is required. Nationwide methods should be clearly described in either a stand-alone Alzheimer policy or plan, or by implementing a plan and policies into existing healthcare, psychological health, or old- age policies (World Health Organization).

Alzheimer's care is demanding and necessitates time, energy, and, in many cases, physical work on the part of the caregiver. Because the condition proceeds slowly, family members frequently

give care for many years and are under a lot of stress for extended durations. The chronic weariness associated with giving lengthy hours of care without breaks exacerbates the consequences of high stress levels. Affection is a powerful motivator for caregivers of persons with Alzheimer's. In the EUROFAMCARE survey, "psychological bonds" love and affection were identified as the main motivation for providing care by 57%, followed by a "consciousness of service" reported by 15% and a "personal feeling of responsibility" recorded by 13% (World Health organization).

Few qualitative studies have been conducted to investigate the impact of stigma on dementia care givers in Asian households. A study indicated that family stigma had a significant and ubiquitous influence on caregiver well-being and functioning among Chinese care givers of people with severe dementia (Chang, 2006). Another research of 32 Vietnamese and Chinese family caregivers of relatives with ad (81 percent daughters and daughters in law) discovered that stigma was substantially connected to disease features and unfavorable preconceptions associated to the elderly (Liu, 2008).

The involvement of family stigma in the stress of caring for someone with Alzheimer's disease has crucial consequences for care givers, professionals, and policymakers. Stigma has a negative impact on caregiver burden. Using this understanding, psychological therapies should aim to lessen caregiver burden by targeting stigmatic attitudes overall and psychological humiliation reactions in specific. In order to offer more effective care, providers of health care and social services should be aware of the consequences of stigma on caregivers of persons with Alzheimer's disease. The general public's understanding of the causes of Alzheimer's disease and associated behavioral manifestations may aid in the propagation of stigmatic reactions and, as a result, the reduction of stigma. If stigma hinders care givers from pursuing help from family, and also institutional services that might decrease their hardship, then supplemental bad outcomes for caregivers, such as depression and physical ailment, along with sudden and unexpected care home arrangement for their family members with Alzheimer's disease, are likely to lead to higher medical costs. A deeper knowledge of the cause and effects of stigma can lead to measures that mitigate its influence (Werner,2012).

Stress is a highly common condition that most family caregivers of relatives with SPMI, regardless of their cultural backgrounds, experience. As a result, it is critical that mental wellbeing psychiatric nurses provide awareness on coping with stress and family mediation to these family caregivers. In order to cope with caregiving and effectively live with the mentally ill relative at home, the

CFCGs typically used a variety of psychological and behavioral methods in their attempts to provide care for the relative with SPMI and endure through it. Most of those CFCGs' assessments of their day-to-day lives and experiences were shaped by established cultures and customs and will be impossible to overcome or modify. Nevertheless, healthcare practitioners must detect and dispel popular misconceptions about disorders and mental illness within family caregivers including their families, which can have a negative impact on the health and well-being of the psychologically ill individual (Chang, 2006).

ALZHMERS IN PAKISTAN

Pakistan is one of these countries, and while dementia research is being conducted, it appears that the country is not focused on the current paradigms. The general public in Pakistan is mostly unaware of Alzheimer's disease. In a culture where older people are expected to relinquish their responsibilities beyond a particular age so that their offspring may assume them, any difficulty with mental, behavioral, or emotional disability is not widely recognized. Alzheimer's disease is not the same as diabetes. It is not widely known in contemporary culture. People do not perceive it as a physical issue" " In this culture, where any individual with a mental illness is simply referred to as Pagal (crazy), Alzheimer's disease is not regarded as a major concern. We do not adequately teach about mental health concerns" (Aurooj,2022).

Because Muslims constitute the majority of the population in Pakistan, religion, culture, and beliefs are extensively promoted in the country. As a result, understanding of mental health issues is quite poor" (Khan,2017). Individualism appears to be popular in Western civilization, but it does not appear to be prominent in Pakistan's sociocentric culture, in which people's perceptions of themselves are strongly linked to societal viewpoints (collectivism) (Cipriani, 2017) .

The indigenous community has its own set of rules for everything from everyday life to dwelling arrangements. A patriarchal form of living linked to a combined family arrangement with two generations living altogether. It demonstrated that elderly people, particularly older men, are held in higher esteem and have the authority to make important decisions about religious and social responsibilities for all other family members. Alzheimer's disease in these elderly people has the potential to spread disorder in the entire family (Hossain,2020).

Alzheimer's dementia may be more known to patients and caregivers than some other dementias. Nonetheless, Alzheimer's disease is by far the most prevalent kind of dementia. It might also imply that, due to a lack of experience among health care workers in this area, more persons are labelled with Alzheimer's dementia than with other varieties of dementia. This data is critical for developing awareness programs and enhancing medical practitioner education. All patients and caregivers agreed that forgetfulness was the most prevalent and painful characteristic of dementia (Khan, 2017).

According to the findings of a dementia registry research published in Islamabad, Pakistan, 81 percent of individuals with dementia present with loss of memory as the predominant indication. This gives useful information on people's understanding of recognizing forgetting as a dementia sign, and treatments or managing techniques based on this condition would be desired given it is also regarded to be the most upsetting symptom of the disease (Ahmad,2011). This is an intriguing conclusion because evidence from the western field shows that forgetting is the most common but least unpleasant sign (Fauth, 2014).

In nations such as Pakistan, there is also a scarcity of social science research. In Pakistan, nothing is known about the prevalence and experience of dementia. The 10/66 research initiative conducted population-based dementia research in low- and middle-income nations, although Pakistan was not one of its research locations. With a relatively low life expectancy and even lower healthy life expectancy within the area, the country scores notably poorly in terms of the health of elderly people (Zaidi,2013). With the growing number of older people in Pakistan, as well as their poor socioeconomic condition, there has been relatively little study on issues related to old age, particularly the growing public health concern of and Alzheimer (Zaidi et al. 2019).

To promote for the most successful programs and policies for spreading knowledge and support expert support to those with mild to moderate Alzheimer to reduce their burden and stress, research must be performed to examine people's understanding, beliefs, and attitudes about dementia. The current study tries to fill this gap by using a case study of Pakistan. There is a lack of Alzheimer knowledge and understanding in Pakistan. Alzheimer is still stigmatized, and people have many negative and inaccurate beliefs about it. However, Pakistani society's strong religious affiliations give both strengths and possibilities, and using this network to expand understanding of Alzheimer and associated risk factors at the local and national levels may improve the success of an awareness-raising initiative.

Dementia-related loss of consciousness is fairly widespread in both the general population and the physical work sector. The latter may be attributed to an absence of emphasis on elderly medical training in medical colleges, that enables individual and cultural experiences to determine health services.

The non-discerning eye finds it difficult to distinguish between aging process and Alzheimer's disease (Cankurtaran, Halil, 2006). In Pakistan the vast majority of the aforementioned health sciences degrees do not focus on age-related health issues, notably brain health. However, new programmes are emerging, such as the Sussex Institute of Neuropsychiatry in Islamabad.

Pakistan has a complicated mix of private, governmental, and third-sector health-care institutions, which allows interested individuals or groups of persons to explore a unique interest, such as dementia-related practice or study. While such flexibility may be advantageous, it may be constrained by the prospect of inadequate quality control, a lack of sufficient governance, and the possibility that vulnerable PWD and their families may be jeopardized.

Despite the scarcity of health and social care services for people with disabilities and their families in Pakistan, a few privately held institutions offer care methods outside of the family environment. These typically have a historical or ongoing religious affiliation (for example, the Catholic Church) or are third-sector organizations, such as Alzheimer's Pakistan.

Supporting such groups in research activities may strengthen their reputation with legislators while also creating better tailored dementia treatments. medical services, for example, conduct frequent "vision programs" and "diabetes workshops" in one Karachi care home, Dar el Sekun. However, no "memory camps" or other Alzheimer's programmes have ever been provided. Indeed, it is unclear if any of Pakistan's few nursing institutions are aware of the percentage of their inhabitants who may have Alzheimer (Leroi,2019).

Moreover, there are a few instances of well-established, globally financed third-sector research institutions. For example, the Pakistan Institute of Living and Learning. (PILL,2018) For some years, and the Institute of Psychiatry Rawalpindi have been doing globally supported high-quality mental health research in partnership with local, national, and international university partners.

CHAPTER 3

METHODOLOGY

The current chapter, research technique, aids in comprehending the full study procedure. There are several approaches for conducting research. A study uses a variety of strategies to pick cases measure and monitor social life, collect and refine data, analyze data, and report on results. Methodology and method are inextricably related and interdependent (Neuman, 2014).

The present chapter, research technique, assists in understanding the entire research procedure. There are many other methods for conducting a study. It is on three premises. Initially, since reality exists outside, one must use a specific lens to identify it. Moreover, direct observation is the greatest way to determine the precise reality, and finally, material justifications are sufficient for observable happenings.

The purpose of this chapter is to offer a comprehensive overview of the current topic. The study's approach, whether deductive or inductive, is determined by the nature of the research issue. The researcher employed qualitative methods to address this question. So, in the anthropology field, there are several ways that the researcher uses in order to get legitimate data.

RESEARCH METHODOLOGY

The current study employs qualitative technique. It is the greatest and most beneficial way to have a deeper grasp of any phenomena. This is useful for gaining an emic viewpoint and uncovering the hidden reality behind human behavior. Because it is based on reality, it is referred to as unstructured and unplanned study.

- Inductive approach



- Qualitative methodology



- In-depth interviews and case studies

RESEARCH APPROACH

The researcher chose a philosophically interpretative perspective based on the facts provided so the researcher employs an inductive technique in the present study as, for qualitative data, the inductive technique is the best and most widely employed. According to (Punch, 1998) inductive technique is beneficial to condense raw textual information into a concise review form. This method allows researchers to make obvious relationships between the assessment, study objectives, and conclusion.

The inductive technique employs qualitative approaches, such as in-depth interviews, to assist researchers in developing themes and then analyze information. This entire method assist researchers in developing a framework of study that is visible in the original data.

This method is used in the present research to collect qualitative data, which is then analyzed. Because it is less difficult in terms of discoveries and evolution. According to (Thomas,2006) the inductive technique is seen to be easier and more straightforward than other approaches

QUALITATIVE METHODOLOGY

This approach is utilized in the present study to gain an in-depth insight of the respondents' hidden perspectives. The primary reason for picking this qualitative approach is the research's distinctiveness. It is preferable and most beneficial to have a deeper grasp of any occurrence. This methodology is useful for gaining an emic viewpoint and uncovering the hidden reality behind human behavior. Because it is based on reality, it is referred to as unstructured and unplanned study.

As part of an in-depth interview, I intended to unearth the truth and explain occurrences based on first-hand facts. In qualitative technique, this method is well-known. Qualitative approach is

critical for analyzing first-hand data in a socio-cultural situation. This practice aids in making reality evident to both the investigator and the reader (Neuman,2014).

RESEARCH TECHNIQUES

An anthropological approach frequently utilizes a number of qualitative approaches to collect data that may be used in any investigation. The primary qualitative anthropological data collection techniques used in this research are participant observation, key informant, rapport building and data analysis.

PARTICIPANT OBSERVATION

In anthropology, participant observation is referred to as the fieldwork technique. It is utilized in current research to observe people's actions. This approach can be used at many phases of an evaluation. To begin, identify the problem in order to uncover it, and then evaluate it since things are witnessed directly. It is critical for researchers to travel to the field and spend a few days there. In the current study, the researcher gathered data mainly from the PIMS hospital in Islamabad and also asked respondents to permit researcher to visit their residences, which were located in both Islamabad and Rawalpindi. However, it was quite difficult for the researcher to study them from morning to night, because of the "Pardha" of other family members, particularly men "Pardha" is a component of Pakistani culture. Respondents did not consent to this, although they were delighted to be questioned and allowed to stay for a few hours. During this period, I observed their behavior, gathered information, and requested case studies. Difficulties the researcher's experience during participant observation was that some respondents refused to allow the researcher to take photographs of them, while others refused to allow the researcher to record audio of their responses to the questions the researcher posed to them.

By monitoring individuals, the researcher may evaluate actual behavior in real time. This genuine information is gathered, and theme knowledge is enhanced by collecting case studies through in-depth interviews (Kawulich, 2015).

KEY INFORMANT

When the researcher travelled to the field for the current study, the first thing researcher did was look for important informants. A key informant is a well-informed source of information. In the current study, the key informant's researcher picked two health practitioners, one neurologist and the other a psychologist, and the major key informant was the neurologist's P.A in the OPD of neurology, where most Alzheimer's patients come for their monthly visit. As a result, the key informant first introduced the researcher to the doctors (the other two key informants) and also briefed the researcher about the hospital's surroundings. He also provided the researcher a place to wait for the patients and assisted the researcher by introducing him to Alzheimer's patients' caregivers.

In the beginning, he assisted the researcher in establishing rapport in the hospital. Second, key informants from the health care system assisted the researcher by informing about the schedules of Alzheimer's patients. They also provided information regarding Alzheimer's and how care givers are affected in Pakistan. This type of information aided the researcher in the current study.

RAPPORT BUILDING

In Anthropology, the most successful approach for making relationships and revealing hidden truths about a topic is rapport building. The contact between the researcher and the respondent is considered formal if this tool is not used. Respondent is wary of the researcher since he or she is an outsider with whom he or she has not developed rapport (Neuman, 2014; Thomas, 2006).

The key informant, who worked as a PA for a female doctor in the neurology department OPD, assisted the researcher in developing rapport. The key informant introduced me to the physicians, along with a few of the patients. When a researcher first enters the field, he or she uses this instrument based on common experience to build rapport with the respondents. As a researcher, you should be able to break the ice at this time. Before travelling to the field, I concentrated on my clothing pattern. I was initially anxious, but after some time I was able to overcome my nervousness and begin my interview by telling them about myself and how one of my close

relatives is also suffering from this condition and how he inspired me to pursue research on the issue. After that, I began the interview with easy questions. After building rapport, informants grew calmer. In addition, I actively controlled my hand gesture. Rather than interrupting and commenting on respondents' responses, researchers should listen more. This is something I also tried. Another technique used by the researcher to build rapport and to get more information on the topic was probing.

PROBING

This is a critical tool in anthropological research, particularly in case studies and focus group discussions. It functions like a matchstick, as it assisted the researcher in the present study in gathering more relevant information. For this, the researcher provided respondents extra opportunities to speak. The researcher also utilized facial expressions and phrases such as "hmmm", "awwww", "ohho", "ha..Han" and "ooo ". This strategy aided in the discovery of more detailed and in-depth information. Probing inquiries were intended to elicit in-depth thought on a given issue. They are usually open-ended inquiries, which means that the responses are mostly subjective. Probing questions are designed to encourage critical thinking as well as to elicit the respondent's own views and feelings about a certain issue. In the present study the researcher also some probing questions include “What makes you believe that?”, “What effect do you believe this thing had on you?”, “Do you think this is right?”, “Why do you think that way?”

For instance, when one of my respondents was telling about the care centers that

“Humary mashray ma bohat bura samja jata ha agar ma apne shohar ko kisi aur kay hawale karon kayal rakhnay kay lia” ... “in our society people talk bad about those who put their relatives in care centers...”

so, I added a probing question “Ap ko Kun asa lagta ha kay humary mashray ma care center ko bura samja jata ha?” “Why do you think that way?”

The responder provided more information about the topic we were discussing in response to the researcher's probing inquiry.

TOOLS FOR DATA COLLECTION

To collect data, the researcher uses a variety of tools which include interview guide, in-depth interviews, case studies, focus group discussion, video and audio recording, photography, field notes. In the present study the researcher has also employed a variety of data gathering tools, which are described below.

INTERVIEW GUIDE

An interview is a data collection tool. In the current study, the researcher created a semi-structured interview guide and asked open-ended questions to respondents for one and a half hours in a comfortable setting. The interview guide was created by the researcher in accordance with the study's themes. During the discussion, the researcher discovered additional themes introduced by the informants. The interview guide is created by the researcher to elicit elaborative responses in the current study or any other qualitative research. The researcher does not constrain or refine the respondents; rather, the respondents are free to respond. As a result, when the researcher requires diverse and comprehensive data, we ask questions in the form of an interview guide. Another advantage of using an interview guide is that the list of questions the researcher asks the respondents is oral, which can easily create a conducive environment for engaging someone to comment on a specific topic.

A semi-structured interview guide is a valuable tool for data collecting in anthropological qualitative research methodologies. This study was conducted through in-depth interviews using a semi-structured interview guide. Three data collecting instruments were used a semi-structured interview guide for caregivers of persons with Alzheimer's, a semi-structured interview guide for those with no experience with Alzheimer's and semi structured interview guide for key informants. All of these instruments were developed in English and then translated into Urdu.

IN-DEPTH INTERVIEWS

I utilized this strategy to get information about the current issue. In-depth interviews using open-ended questions try to capture the respondent's intellectual and practical environment. Individual

interviews allow participants to share their feelings on the issue. Prior to the interviews, I created a semi-structured questionnaire. There was open-ended interview guide created. To prevent becoming sidetracked, researcher utilized various strategies to get back on track. Before and during the interview, the researcher established rapport in order to obtain accurate and dependable information.

The researcher performed 15 in-depth interviews with caregivers and 20 with members of the general public. All responses were attentively listened to by the researcher. Some interviews were recorded, and the researcher also made notes throughout the interviews.

FIELD NOTES

This is yet another instrument utilized in qualitative research (Creswell, 2007; Thomas, 2006). During the initial days in the field, the researcher studied the entire environment, particularly way of life and all activities related to the issue. As mentioned in my field notes one of my respondent 55 years old who was taking care of her father cryingly said

“Log mujy katy han yay pagal ho gaye han in ko pagal kahany dakil kara do, koi meri madad ni karta mery bachy meri thori madad karty han likn agar koi meri pasay kay zariye say madad kary tu ma bohat sukar guzar hon gi”

“People say to me that he is mad, and tell me to admit him to the mental hospital. No one is there to help me. My children help me a little. If someone could help us with money, I would be very thankful.”

These kind of field notes helped to remember and analyze the intense emotions of the respondents. Field notes are quite significant in the whole investigation. For instance, it serves as proof that the researcher carried out the fieldwork correctly. Furthermore, it is beneficial for interpreting data. moreover, the researcher is competent to defend himself/herself in viva since he/she is knowledgeable about the subject.in present research, the researcher took detailed field notes. Taking notes and recording aided the researcher in writing the discussion as it is.

PHOTOGRAPHY

Photography is used to support field research (Neuman, 2014). It is an important tool that gives readers a better grasp of the surrounds, environment, and physical atmosphere of the location. It also aids in the creation of an image in the minds of the readers in order to keep them properly informed of the location. During my fieldwork, I photographed OPD of the hospital also a few respondents allowed me to take pictures of them.

SAMPLE AND SAMPLING TECHNIQUE

The current study's sample consists of 15 caregivers (males and females) of Alzheimer's patients and 20 members of the general public (10 males and 10 females) and the age limit of the respondents was 24 –70 and the data collected from PIMS Islamabad. The sample covers middle class people of Rawalpindi and Islamabad. A sample is a population that is reflective of the overall population (Creswell, 2007). Purposive sampling was utilized by the researcher in this research. This method is utilized in both qualitative and quantitative studies. Purposive sampling, also known as judgmental and selective sampling, is a sampling approach used by qualitative researchers to find participants who can offer in-depth and thorough information on the topic under inquiry. It is very subjective and defined by the qualitative researcher who develops the qualifying criteria that each participant must meet in order to be accepted for the research study. In the present research this sampling technique is used as the researcher herself inquired about the respondents if they are eligible for the data that the researcher require.

DATA GATHERING

To generate insights, qualitative research employs non-measurable data sources and relies heavily on observation techniques. It is primarily used to respond to inquiries that begin with "why?" and "how?" Focus groups, observation, written records, and individual interviews are examples of

qualitative data gathering approaches. The research interviewed 15 caregivers and 20 members of the general public. Three key informant interviews were conducted.

DATA PRESENTATION

The deductive approach and the inductive approach are the two primary ways to interpreting qualitative data. Deductive techniques entail analyzing data using a structure or planned framework. Essentially, the researcher imposes their own structure or beliefs on the data and then analyses the interview transcripts using these. Although this technique is quick and simple, it is rigid and has the ability to skew the whole analytic process because the coding framework has been determined in advance, which can significantly limit theme and theory development.

The inductive technique, on the other hand, includes analyzing data with little or no predefined theory, structure, or framework and relying on the data itself to establish the structure of analysis. This strategy is extensive and hence time-consuming, and it is best suited when little or nothing is known about the phenomena under research. The most popular method for analyzing qualitative data is inductive analysis. While there are alternative approaches for analyzing qualitative data, the methodology utilized in this study is thematic analysis technique (TAT), which is perhaps the most commonly used form of data analysis in qualitative work.

As previously indicated, the current study employs an inductive method of qualitative research, collecting data through in-depth interviews and analyzing it thematically using the theme analysis technique (TAT).

DATA ANALYSIS

For data analysis in this study, the researcher used the Thematic Analysis Technique (TAT). Data was gathered by the researcher through various techniques but the main techniques used were participant observation and in-depth interviews. Before going into the field, the researcher created a rough conceptual model. Secondary data and a pilot study were also used to generate indicators, which were then used to collect data on the topics. TAT was then used to extract hidden messages

from interviews. The technique entails examining transcripts, finding themes within the data, and collecting instances of those topics from the text. Interview transcripts, field notes, and observations give a descriptive overview of the research but no explanations. The researcher is responsible for making sense of the obtained data by studying and analyzing it. The research was divided into two parts: family caregivers of persons with Alzheimer's and the obstacles they have faced, what assistance they have and would want to have, barriers to receiving care services, how Alzheimer's impacts them, and their knowledge and perspectives on day care centers. Members of the general public and their perceptions of Alzheimer's disease, the stigma associated with the disease, and their opinions and knowledge about day care centers.

ETHICAL CONSIDERATION

Qualitative research necessitates that the researcher conducts his/her research in an ethical manner, ensuring that all rules and laws are observed. Anonymity, confidentiality, and informed consent are three essential ethical problems to consider while doing qualitative research. Ethical Norms also support research goals such as knowledge, truth, and error avoidance. Prohibitions on creating, manipulating, or misrepresenting research data, for example, promote the truth while minimizing mistake. Ethical principles in research also aid in the development of public support for research. People are more willing to finance a research study if they have confidence in the research's quality and integrity. Many research standards support a range of other essential moral and social ideals, such as social responsibility, human rights, and so on. In the current study, ethical considerations are taken into account, and the researcher has attempted to adhere to all of the criteria established by the ethical committee.

INFORMED CONSENT

Informed consent has been acknowledged as an essential component of ethics in research conducted in a variety of areas. It is critical for qualitative researchers to establish ahead of time which data will be gathered as well as how they will be utilized. The idea of informed consent

emphasizes the researcher's obligation to fully educate participants about all components of the research in understandable language. Explanations must address the following topics: the nature of the study, the possible involvement of the participants, the identification of the researcher and the funding organization, the research purpose, and how the findings will be reported and used.

In the current study, before conducting the interview, the researcher obtained permission from the respondents and also told them about myself and why the researcher is conducting this study. and what is the purpose of this study? The researcher also obtained permission before recording the conversation and taking any photographs. If they approved it, the researcher also requested for permission to visit their home.

All sorts of study require informed permission. It is a vital idea that must be remembered at all times. Participation in research must be entirely voluntary. This is referred to as the concept of voluntary consent (Richards & Schwartz, 2002).

ANONYMITY AND CONFIDENTIALITY

Quite a large number of detailed personal information is usually gathered in qualitative research. While doing so, not only are there practical hurdles to obscure the information, but certain contextual data is also required for analysis (Richards & Schwartz, 2002). Before adding their personal information, the researcher must obtain consent from the respondents. The researcher is not permitted to communicate their sensitive knowledge with anybody else

CHAPTER 4

AREA PROFILE

Any research project involves two sorts of data: primary and secondary. Primary data is acquired from a specific location. The purpose of this chapter is to create a complete image of a given location while maintaining a demographic and ecological approach to uncovering people's beliefs. Because it gives accurate information about the study topic, the area profile provides an appropriate framework for the reader's help. It discusses the geographical, historical, and socioeconomic status of the current area. This chapter deals with the area Islamabad and the locale is PIMS hospital OPD section (neurology department) where the research has been conducted.

LOCALE

According to the demands of the research, PIMS hospital of Islamabad was selected as the research locale. Researcher selected this hospital for following reasons:

- PIMS hospital is a government hospital and patients come there for checkup from different regions indicating diversity in the patients. When we talk about the Alzheimer's patient, they mostly come to hospitals for their monthly check up and they are not registered there so the research was conducted in the OPD section (neurology department) the hospital.
- The second reason for choosing this location was its geographic accessibility. Because this hospital was conveniently accessible to the researcher and data could be quickly acquired, this location was chosen.
- Another reason for selection of this site was researcher's reference and familiarity with the locale as one of the relatives of the researcher who is also suffering from Alzheimer's also gets his monthly checkup from there.

ISLAMABAD

Islamabad is one of Pakistan's most attractive and sophisticated cities. It serves as the country's capital as

well as a center for prominent attractions, institutes, and other specializations.



FIGURE 1: ISLAMABAD (SOURCE GOOGLE <https://www.thenews.com.pk/>)

HISTORY

Islamabad, Pakistan's capital city, is situated on the Potohar Plateau in the country's northwest. This place has historical significance due to its location at the crossroads between Rawalpindi and the North West Frontier Province. The city was created in 1960 to replace Karachi as the capital of Pakistan, it has held since 1963. Islamabad and Rawalpindi are considered sister cities due to their close proximity.

LANGUAGE

Punjabi, Pushto, Potohari, and Urdu are among the languages spoken by the ethnically diverse community. English is widely spoken, and the population of Azad Kashmir, Gilgit Baltistan, and federally administered tribal areas is relatively small. Islamabad has a distinct culture as a result of its citizens' migration from other parts of the nation. As a result, the city boasts a diverse religious and cultural population.

Punjabis account for 65 percent of the population, followed by Urdu-speaking Muhajirs (14%), Pashtuns (10.51%), and others (including Sindhi, Balochi, and Kashmiris) accounting for the remaining 7%.

CLIMATE

Islamabad's climate is classified as humid subtropical. The spring season brings dry and warm waves, while the summer months, which coincide with the Mon soon, are humid. Winters do not last long, yet they leave a chilling effect. The most well-known are Rawal Shamili and Kanpur Dam. The city of famed Margala Hills Islamabad is placed 33.43N 73.04E. From Pothohar Plateau for the purpose of artificial management of areas microclimate. The region's distinctive appealing geography increases the region's appeal to both locals and visitors.

DEMOGRAPHY

As of 2016, Islamabad has a population of 1,433,000 people. More than 4.5 million people live in the Islamabad-Rawalpindi metropolitan area, which encompasses Islamabad and its Neighbour Rawalpindi. Despite development that was completed in the 1960s, Islamabad has shown steady population growth over the years. Its high percentage of youthful residents, combined with its climate, scenery, and jobs in sectors including information and communications technology makes it an area that should see continued growth well into the future. Estimates place the 2020 population at almost 1.7 million, and it's expected to exceed 2.2 million in 2030.

People between the ages of 15 and 64 make up the majority of the city's population, accounting for more than 59 % of the total. Over 37% of people are under the age of 15, with the senior population accounting for only 2.73 percent.

RELIGION

Approximately 95 percent of the people being Muslims, Islam is the most practiced religion in the city. Christianity is the second most popular religion, accounting for little more than 4% of the population.

EDUCATION

At 88 percent, Islamabad has the highest literacy rate in the country. Because of the higher education system, which includes 16 renowned institutions, more than 10% of the population has a bachelor's degree, and 5.2 percent has a master's degree.

ECONOMY

Islamabad is a vital contributor to the Pakistani economy, accounting for 1% of the country's GDP while having just 0.8 percent of the population. As per the World Bank's Doing Business Report 2010, Islamabad is the finest place in Pakistan to establish a business. With the construction of two Software Technology Parks, which comprise several national and foreign technical and information technology enterprises, Islamabad has experienced an increase in information and communications technology.

HEALTH CARE

Islamabad has the lowest infant mortality rate in the country, with 38 deaths per thousand compared to the national average of 78. There are both public and private medical facilities in Islamabad. Pakistan Institute of Medical Sciences (PIMS) is Islamabad's largest hospital and hospital was established in 1985 as a teaching and medical training center. PIMS is a National Reference Center that provides specialized diagnostic and therapeutic services. These services include:

| | | |
|---|---|--|
| Accident and emergency | Gynae/Obstetrics | Pathology |
| Anesthesia | Hospital management Information system | Pharmacy |
| Blood bank | neonatology | Plastic surgery |
| Cardiology | nephrology | Psychiatry |
| Dentistry | neurology | Pulmonology |
| Dermatology | E.N.T | Gastroenterology |
| ophthalmology | Neurosurgery | GEN.medicine |
| Urology | Oncology | Radiology |
| Pediatric surgery Orthopedic surgery | GEN.Surgery | Rheumatology/ physical medicine |

TABLE NO 1: DEPARTMENTS OF PIMS.

Islamabad Hospital (IH) is the mainstay of the Pakistan Institute of Medical Sciences. It has a capacity of 592 beds and 22 medical and surgical specialties. Islamabad Hospital's vast, centrally air-conditioned OPD opened on December 18, 1985, followed by inpatients and an accident and emergency center in October 1986. In September 1987, it was solemnly launched by then-Prime Minister Muhammed Khan Junejo. It has a covered area of roughly 356976 square feet. The Administration building is on the ground floor.



FIGURE NO 2: PIMS HOSPITAL (SOURCE: BY RESEARCHER)

ENVIRONMENT

The hospital's general environment is not very excellent, since it appears to be overcrowded all of the time. since the patients come from all around. Because there are several OPDs in the same location, the OPD part of the hospital are overcrowded, understaffed and Patients must wait for hours for their turn for a checkup, however in this case, patients with Alzheimer's and dementia find it impossible to wait for hours, making it even more difficult for caregivers to calm their patients. Most of the time, the physicians are late, and most of the time, the doctors take more than a half-hour tea break, keeping patients waiting.



FIGURE NO 3: OPD SECTION OF THE PIMS HOSPITAL (SOURCE: BY RESEARCHER)

DEMENTIA / ALZHEIMER'S DAY CARE CENTERS IN ISLAMABAD

In Islamabad, there are extremely few Alzheimer's and dementia-specific childcare establishments. These include holistic health care services and the second home (fraternity old age home), which are dementia and Alzheimer's care centers. There are numerous day care centers, old homes, and rehabilitation centers for other mental illnesses and drug addiction, psychiatric treatments, and counselling, such as happy life psychological services, self-care trust international, Psych Care, Mental Health Services, and so on, but there are very few such care centers or even hospitals for Alzheimer's and dementia. There is a famous organization by the name Alzheimer's Pakistan and its branches are in Lahore, Karachi, Peshawar and Rawalpindi and this organization might open their care center in Islamabad soon will be a great help to the people. Moreover, there are a few instances of well-established, globally financed third-sector research institutions. For example, the Pakistan Institute of Living and Learning. (PILL,2018) For some years, and the Institute of Psychiatry Rawalpindi have been doing globally supported high-quality mental health research in partnership with local, national, and international university partners. Alzheimer's Pakistan has

also contributed to the study. For instance, they recently concluded a collaboration research with the University of Southampton and Brighton and Sussex Medical School in the United Kingdom called "Understanding, Beliefs, and Treatment of Dementia in Pakistan." For numerous years, and the Institute of Psychiatry Rawalpindi have partnered with local, national, and international university partners to conduct globally sponsored high-quality mental research programs. PILL has taught between 300 and 500 researchers in psychiatric research methods, research study execution, and management over the last 20 years, both inside the agency and for other organizations. The appropriate approach would be to increase capacity and trained and developed staff for Alzheimer's work.



FIGURE NO 4: INSTITUTE OF ALZHMERS PAKISTAN (SOURCE: <http://alz.org.pk/>)

CHAPTER 5

COPING MECHANASIM OF FAMILY CARE GIVERS

Caring for and supporting someone with dementia and Alzheimer's is not solely the responsibility of the person's family and others in their immediate network. Communities, authorities, and society as a whole should all be concerned about it. The unawareness and responsibility indicate that this is not the case in practice. Family caregivers' significant contribution is frequently undervalued and underappreciated. In most cases, the majority of caregivers are spouses, and women make up the majority as compared to men. Women predominated as caregivers in the 10/66 Dementia Research Group population-based study conducted in 11 sites across Latin America, China, and India, with the exception of rural China (Prince, 2008)

Family caregivers in the home are assigned with a variety of tasks that change as the disease progresses. As the disease progresses, the level of support typically increases, initiating with guidance with instrumental daily living activities (household, financial, and social activities) and progressing to include personal care and, eventually, almost constant supervision.

Dementia care is challenging and necessitates time, energy, and, in many cases, physical effort on the part of the caregiver. Because the condition worsens slowly, family members frequently provide care for many years and are under a tremendous stress for extended periods of time. The fatigue associated with providing long hours of care without breaks exacerbates the effects of high stress levels.

The most of caregiving studies puts emphasis on the adverse factors. Burden occurs when trying to cope resources are exhausted. As a result, it is critical to document that the vast majority of family and friends involved in informal care are proud of their roles and see various advantages.

One of the most important aspects of this study is the stress that caregivers experience while caring for the patient, as this disease necessitates long-term care, which is exhausting for caregivers. This study examines the experiences of care givers of people living with dementia and Alzheimer's disease. How are the patients being cared for?

If the person continues to live in the society, caregivers will generally require specialist care in the later stages. This is particularly true when caregiving necessitates major physical input and when the psychological impact necessitates caregiver temporary relief in order for them to remain in their role for as long as necessary (WHO,2012).

The researcher discovered in this study that caregivers do not consider caring for their patients to be a hardship. Affection was an important motivating factor, and also, they believed that it is their responsibility to care for their relatives. Some believed that caring for a relative was a religious obligation, and the majority of them were women whose husbands had Alzheimer's disease and believed that if they did not care for their husband, it would be a sin, but if they did, they would be blessed. Bigger families experienced less caregiver strain, most likely because caregiver responsibilities could be shared and caregivers could benefit from temporary relief. The caregivers, who were the patients' children, believed that it was their responsibility to care for their parents and grandparents, as well as a moral responsibility to compensate the parents in old age.

In accordance with the researcher as we live in an Islamic country, and as Muslims, we think in terms of what our religion teaches us, and while our religion does teach us the right path, it does not compel us to put ourselves in danger if we can seek assistance from others. With this in mind, the researcher asked the family caregiver how well they understand the disease and how well they are aware of the associated day care centers and if they had ever sought help from religious scholars or day care centers. Starting with disease awareness, caregivers reported that they became aware of the disease, as well as their responsibilities as caregivers, primarily as a result of a doctor's assessment of their relative, and that they were not aware of this disease prior to the assessment. Caring for someone with Alzheimer's disease can have an adverse influence on the caregiver's cognitive functioning, life span, standard of living, and economic security. The condition can have a significant and frequently negative influence on family relations and role performance. Some caregivers noted that their economic structure was impacted when a relative was diagnosed with this condition, as the majority of patients were the sole supplier of income. Without enough assistance, providing Alzheimer's care can become a full-time job. Caregivers have stated that they are forced to quit their occupations, work fewer hours, or take less tough employment in order to provide care, which has impacted their family's economic situation. Another factor influencing caregiving is a lack of resources accessible to caregivers. The majority of the respondents in this

study come from middle-class households, making it difficult for them to obtain outside assistance or better treatment for their patients. The following table explains the respondents' economic structure.

| MONTHLY INCOME | NO. OF RESPONDENTS | PERCENTAGE% |
|----------------|--------------------|-------------|
| 30,000-40,000 | 4 | 26% |
| 40,000-50,000 | 8 | 53% |
| 50,000-60,000 | 3 | 20% |
| TOTAL | 15 | 100% |

TABLE NO 2: ECONOMIC STRUCTURE OF THE RESPONDENTS

A few caregivers stated that their family relations were also affected by their relative's condition because they could no longer visit them; some of them stated that their relatives blamed them, claiming that they were the cause of their relative's disease; however, the majority of caregivers stated that their relatives supported them.

The respondents were asked if they ever felt the need to hide their relative's condition from their friends and family. The majority of caregivers stated that they never tried to hide this disease from their friends and family, which included nine out of fifteen respondents.

The challenges to caregiver support services are the same as those found for Alzheimer's health and social services in general. These barriers include negative attitudes toward diagnosis and treatment, a lack of properly trained health workers and facilities to scale up assistance, a low standard of help seeking because Alzheimer's is considered normal ageing or stigma, a scarcity policy initiative, and an insufficient funding for Alzheimer's services, research, and training.

Caregivers have extra challenges while looking for assistance for themselves. In Pakistan, there are no easily available support services for family carers. There are challenges to access and uptake, such as a lack of acknowledgement of the caregiver position, a lack of awareness of Alzheimer's disease, and cultural impacts on caregiving.

Inadequate awareness, especially dementia and Alzheimer's literacy, also led to a lack of quality care. The variety of abilities necessary for good health education, such as comprehending medical

language and information well enough to follow orders, recognizing and responding properly to symptoms, evolves with time. Caregivers' attitudes and actions are altered when their health education is inadequate.

It is concluded in this study that relying on caregivers without evaluating their abilities to deliver care might result in a challenging and extremely damaging environment for both the caregiver and the care receiver.

INDIVIDUAL INTERVIEWS OF FAMILY CAREGIVERS

Family caregivers in the home are faced with a variety of responsibilities that develop during the disease process. Generally, as the condition develops, the degree of support rises, beginning with assistance with instrumental activities of daily living (domestic, economic, and social activities) and progressing to encompass personal care and, finally, continuous monitoring. The severity and provision of support required, as well as their improvement over time, are determined by many factors, including the clinical profile (types and severity of memory problems and psychological and behavioral symptoms, which may vary by subtype of Alzheimer's disease), the existence of comorbid psychological and physical problems, the person with Alzheimer's traditions and practices, the person's personality, and relationships.

Family members usually do not consider themselves caregivers, and as a result, they may not seek out options to help them in that capacity. Those who seek such services typically find them fragmented, disorganized, and inappropriate for their needs. However, there is a dearth of understanding regarding such services.

Caregivers for persons with dementia and Alzheimer's face stigmatization of the condition, in addition to fragmented care systems, a lack of awareness about options, and the emotional challenges of care providing. Caregivers and policymakers alike must acknowledge the value and dignity of the caregiving duty.

This section of the study aims to get insights on how family caregivers survive, what difficulties they encounter, and what sort of aid they would be ready to take based on the intricacies of

Pakistan's cultural and religious norms. Following are some themes generated from the objectives of the study.

KNOWLEDGE AND AWARENESS

PATHWAY TO DIAGNOSIS

The caregivers suspected that something was wrong with the relative, so they assessed doctors. Others were advised by friends and family to seek medical aid, and they themselves believed that it was normal as one grew older.

“Mery baba kay ik doast nay humayn Kaha kay hum dad Abu ko doctor kay pass lay Jayn takay doctor in medicines de jin say in kay demag ko takat Milay aur unhe bi ni pata tha kay yay koi bemari ha tu jab yay bemari diagnose hoi tab humay pata Chala kay yay bemari ha”

“.....one of my father's very good friend advised us to take him to the doctor because the doctor would give us medicines to energize his brain, and he, too, had no idea about this disease. So, after being diagnosed with this disease, we were aware of it...” (Mr. Qasim age34)

We were not aware of this disease at first because nobody in our family had this disease before and most of us forget small things like where we put our glasses or what we were going to say or do so it was like this and we never took it seriously (Mrs. Manzoor age56)

UNDERSTANDING OF THE DISEASE

Care givers were asked about their understanding of this condition and what causes it, and the majority of care givers were unaware of it prior to diagnosis. They first learned about this condition when their family member was diagnosed with it.

When asked how they learned about this disease, the majority of them stated that they were ignorant of it until physicians notified them about their relative status, at that point they realized it was a disease; otherwise, they believed it was a normal ageing process. Researcher asked them that were they aware of this disease before their relative was diagnosed of this disease and their reply was like this

“Nahi humayn is bemari kay bare ma ni pata tha Kun kay humari family ma palay kisi ko bi yay bemari ni thi”

“No because nobody in our family had this disease before.” (Mrs. Manzoor 56 years old wife).

“Nahi Abu kay bemar hone say palay ma nay asy kisi ko ni dekha jin ko yay bemari ho”

“No. I haven’t come across any person with such disease before my father.” (Mrs. Zohaib 27years old daughter of the patient).

The care givers had some knowledge of Alzheimer's but there were inaccuracies in their knowledge. Care givers gave different reasons for the causes of this disease which included tension, tragic incident, anger, aging overthinking lack of social interaction loneliness etc. Some of the care givers were not very sure of the causes of the disease.

“Mery kayal ma Zada sochnay aur Akeley rehnay say, her time tension Lene say.hum her time tension lete rehty han aur apne demag pay zor dalty rehty han jis ki waja say asi demag ki bemarkian ho jati han”.

“I think overthinking and being lonely, taking tension all the time, we take tension but when we take tension all the time and on even the slightest thing, we put pressure on our brains which causes such brain diseases.” (Mrs. Nadeem 63 years old).

“Baba kay Bahi ki tragic death kay waqae ki waja say shayad in ko bohat young age ma yay bemari ho gai.”

“He went through a tragic incident of his brother’s death, which was probably a trigger for early on-set of the disease.” (Mrs. Zohaib 27years old daughter of the patient)

“Mery kayal ma Choti Choti cheezon pay gussa karna and bohat zada sochna hi is bemari ki waja bani han”.

“I think getting angry at the smallest thing and overthinking is the cause of this disease.” (Mr. Usman 24-year-old son of the patient)

STIGMA

Some of the care givers agreed that they had initially tried to hide this disease. Because they were afraid of what would people think if they told them that their relative had this disease and they would link it with madness

“G hum nay suru ma is baat ko chupaya kay baba ko koi masla ha her kisi say chuapaya apne hamsayon say aur reshtadaron say ya koi mehman agar a jaye tu us say kun kay hum darte thay kay log humary baba ka Mazak na urrain kay yay bar bar ik hi cheez puchty han ...”

“Yes. We used to hide it initially from everyone including our relatives, our neighbors or any guests that would come to our house because we were afraid that they would make fun of my father that he repeats the same question...” (Mrs. Zohaib 27years old daughter of the patient)

“Suru ma hum kisi ko batana ni chatay thy kay ami ko yay bemari ha likn is say bohat sari galat fehman hona suru ho gain is lia pir jis say bi hum milay humay use batana para...”.

“We didn't want to inform everyone that she had this sickness at first, but it caused a lot of confusion, so we had to tell everyone we encountered...” (Mr. Ishtiaq ahmed,47 years old son of the patient).

“Humy sharam ati thi aur ati ha logon ko batay hoye kay log kaya kahayn gay kun kay demagi bemari ko humari society ma bohat bura samja jata ha...”.

“We were ashamed about what people would say, and we still are since mental illness is considered taboo in our society...” (Mr. Qasim age 34)

The majority of care givers stated that they never tried to hide this disease, which included nine out of fifteen respondents, indicating that this disease cannot be hidden from anyone because the patient's confusion, repetitive questions, and mood swings make it easier for people to understand that something is wrong with the person.

These were some responses of the respondents

“...Suru Suru ma tu kisi ko ni etna pata Chala kay in ko yay bemari ha magar jab inho nay bar bar sawal dohrany suru kiye tu logon ko samaj lagna suru ho gai kay in ko kuch masla ha magar hum any kisi say ni chupany ki kosis ni ki....”

“...At first, no one realized he had this ailment, but as he started repeating a lot of things, our family members and Neighbours got aware but we never tried to hide his condition from anyone...” (Mrs. Manzoor, age 56)

“Nahi kun chupayn hum, zarorat hi ni ha chupanae ki logon ko kud hi pata chal jata ha jab yay bar bar ik hi sawal karty han ya achanak say Rona suru ho jatay han aur ik dam say gussa ho jatay han choti choti baton par. likn logon bemari kay bare ma zada ilm ni ha likn yahi katy han log kay in ka demag sahi say kam ni kar Raha....”

"No, why would we hide. There is no need to conceal this sickness; people were aware of it when he used to repeat questions, cry unexpectedly, and become enraged over the tiniest of things, despite the fact that they were unaware of the disease; they concluded that his brain was not working normally...." (Mrs. Zulfiqar age 63)

When they were asked about whether the memory and psychological problems are stigmatized in our society or not and most of them agreed to it.

“Humy sharam ati thi aur ati ha logon ko batay hoye kay log kaya kahayn gay kun kay demagi bemari ko humari society ma bohat bura samja jata ha...”

“We were ashamed about what people would say, and we still are since mental illness is considered taboo in our society...” (Mr. Qasim age34)

Another respondent, the patient's daughter, responded to our inquiry. “G log aksar dono terms Alzheimer's aur psychological issues ko same aur normal cases samajty han jo kay haqeeqat kay bilkul mutaradif ha psychological issues aur psychological jo behaviors hoty han un ka ilaj ho sakta ha aur log bohat jaldi theek ho jaty han magar Alzheimer's tu long term bemari ah is ka ilaj hi ni ha aur yay wahid asi bemari ha jis ma bohat Sabar ki zarorat hoti ha yay ik Aam bemari ni ha aur isy am bemari kai tarah bi ni treat karna chaye”.

“Yes. People usually call both the conditions to be same. They would term both psychological problems as well as dementia or Alzheimer’s as ‘normal’ case, which is totally opposite to reality. Psychological issues or psychological behaviors can be cured and people may recover really fast. But I think that Alzheimer’s takes time and it’s a rare case that needs lots of patience. It's not a normal disease. So, it shouldn’t be treated that way either.” (Mrs. Zohaib 27years old daughter of the patient)

The researcher next questioned respondents if they had ever felt that people made fun of their relative when he or she was unable to accomplish even the most basic chores, and what their relatives' and people around them reaction was when they found out that he or she was suffering from this disease. Caregivers, had mostly seen negative public responses such as abuse, not caring, people making a mockery, some using stigmatizing words, some are not visiting anymore, and talking bad behind their backs.

“Meri family ma palay is bemari kay bare ma kisi ko bi ni pata tha is waja say jab family members ko pata Laga tu un honay

bohat strangely react kia aur meri ami par ilzam lagaya kay unho nay jado karwaya ha mery dada abu pay....”.

“In my family, no one had ever heard of this disease before, so they took it extremely strangely at first. My mother was also accused of doing black magic on him.....” (Mr. Qasim age34)

“ami bohat sawal Karti thi suru ma tu logon ko lagta thay yay Mazak kar rahi han aur log tu irritate bi ho jaty thy....”.

“She used to ask repetitive questions people at first used to think that she might be joking or some of them get irritated...” (Mr. Ishtiaq ahmed,47 years old son of the patient)

According to one of my respondents their family got negative reactions and responses to their father's disease and she says

“G jab logon ko pata laga kay baba kay Sath yay masla ha kay wo bhool jaty han ya confuse ho jaty han tu Jan bujh kay baba say muskil aur tricky sawal puchty taky wo baba ka Mazak Urra sakayn ya un ko sharminda kar sakayn.... woh is situation ko nahi samajte jis se family aur care takers guzar rahay hain kyunkay woh is se ziyada relate nahi kar satke. yahan tak ke hum ne dekha hai ke log hamein kehte hain ke hamaray baba ko subah neend ki medicine do taakay woh din bhar so jayen. jabkay inhen is baat ki koi parwah nahi ke woh raat ko soty hai ya nahi”.

“Yes. When people learned that he is suffering from this disease then they would ask manipulative and tricky questions to embarrass our father on purpose..... They don't understand the situation the family and care takers are going through because they can't relate to it much. We have even seen people telling us to give sleep medicine to our father in the morning so that he would sleep throughout the day. While they don't care whether he sleeps at night or not....” (Mrs. Zohaib 27years old daughter of the patient)

On the other hand, Some Caregivers have had favorable reactions from the neighborhood and family, such as members supporting, being kind, sympathizing, and worrying and also praying for the person with Alzheimer's, as well as being respectful and tolerant.

“boht sare log dukhi han mery husband kay lia kun kay yay har time active raty thy har ik ki madad karty thy bohat bahadur aur naram dill insan thy aur har kisi kay sath achay taluqat thay paroosion kay Sath Rishta Daron kay sath har ik kay sath”.

“Most of the people are sympathetic because my husband used to be a very active, kind and brave person and had good relations with the neighbors as well as relatives.” (Mrs. Riaz age 65)

“Jab humary relatives ko pata laga kay baba ko Alzheimer’s ha un ko tu palay samaj hi ni lagi kay yay ha kaya tu un ho nay baba ko kaha kay ap burahy ho rahay han isi waja say ap bhoolna suru ho gaye han aur har koi hamesha yahi keta ha kay is bemari ki waja jadu ya Nazar ha. Magar yay ni ha kay unho nay meri ya meri family ki madad ni ki balky mery kafi relatives bohat supportive han aur jab unhe samj lagi kay baba ko asi bemari ha jo din badin barhti ja rahi ha tu unhe bohat afsoos hoa...”.

“When most of my relatives knew that he is suffering from this disease they didn’t at first understand what is this disease they said you are getting older that is why you started forgetting this disease and they always relate it to black magic or evil eye. But it's not that they didn’t offer me or my family any help. Most of them are very supportive. They were sad when they knew that my father is suffering from a disease that is progressing day by day.....” (Mr. Usman 24-year-old son of the patient)

CASE STUDY

Mr. Qasim, 34, has been caring for his grandfather, who has Alzheimer's, for the past 7 years. He was initially diagnosed with dementia, which led to Alzheimer's, and he began discussing with us by telling us about his connection with his grandfather. When I was a kid, I'd grasp my grandfather's finger and we'd go on leisurely strolls around our neighborhood. I'd feel weary soon,

so he'd buy me some candy and a fizzy drink to keep me going. He adored me, and I adored him. He used to adore me a lot because I was his only grandchild, and he would fulfil all of my wishes. As time is passing by, his memory has begun to fade, and I am observing him as a young man as he is gradually forgetting about me as a tiny child. He is steadily deteriorating, and it is becoming more difficult to care for him. Now he has no recollection of me and regards me as a stranger in his room. It hurt. We couldn't understand why he was forgetting things at first because all we knew was that he was getting older, but as the disease progressed and his sudden mood swings and constant questions made us worried, one of my father's very good friend advised us to take him to the doctor because the doctor would give us medicines to energize his brain, and he, too, had no idea about this disease. So, after being diagnosed with this disease, we were aware of it, but we did not inform everyone in the family.

Except for my mother, he has forgotten many members of his family. Strangely, he didn't have a good connection with my mother while he was well, but now he trusts her. I don't understand why? Maybe he only remembers her or senses her maternal touch. Initially, he began to forget the date and day; gradually, he began to forget things; he began to forget the way to his home; and now, he has totally forgotten where he resides. He always wants to go home, but he forgets he is already there. It is difficult to deal with his violent conduct at times. My grandfather had many terrible and painful situations in his life, but he refused to discuss them and taking stress of those thing affected his brain.

I assume he felt he could manage things on his own, but those difficulties were buried for many years, and now that he is old and frail, they have all resurfaced, which is what causes a condition like this. He can no longer bear them and begins to mourn and grieve over them. It is quite difficult for us to deal with Alzheimer's. We were ashamed about what people would say, and we still are since mental illness is considered taboo in our society, I believe, but most importantly, we don't know what to do or how to care for him. We can't even put him in a day care facility or pay a professional to care for him since our family would gossip about us if we don't take care of him. Regardless of how much we care for him, he never improves. He's just deteriorating. The work of a caregiver is both difficult and emotionally draining.

You can watch your loved one fading away. It's also distressing for caregivers, who require assistance and support. In our society, mental illness is so stigmatized that we can't even talk about

it freely. In my family, no one had ever heard of this disease before, so they took it extremely strangely at first. My mother was also accused of doing black magic on him. However, my mother looks after him the most of the time when my father is at work, and I have lately joined my father's shop as well, which is a clothing store in Saddar Rawalpindi. However, because my mother is unable to take full responsibility for him, I assist her by accompanying him to the washroom, assisting him in taking a bath, and assisting him in changing clothes, which appears to be simple tasks but is not because this disease makes it difficult for the patient to understand what the other person is attempting to say.

Most of the time, he does not agree with what I say to him, which is stressful and exhausting. Most of the time he wants to go out since he doesn't know this place, and it's tough to stop him because he never agrees and insists on going home, and in this circumstance, he gets angry and violent, but now that he's frail and old, he can't harm anyone, but he still tries. Every day is spent this like sometimes he won't agree to eat his medication and if he doesn't take medicine he can't sleep and as a result we can't sleep either, especially I can't because I sleep in his room with him.

No, I don't believe he's a burden, but my family and I get stressed out at times and get furious over little things because we have to lead him through everything, but we never think he's a burden since it's our duty to take care of him.

I believe we should raise public awareness of this disease, as well as all other mental diseases. We should also teach people that we are not accountable for someone else's disease unless it is contagious. We should not blame each other; instead, by educating everyone in our society, we will make it easier for people like us to seek external help. Aside from medical assistance, we also seek assistance from religious organizations. Every week, a Qari sahib from our neighborhood sends a hafiz e Quran who recites Surah Rehman beside grandfather. This is really beneficial to us since we feel lighter, calmer, and less stressed for a few days.

I believe we should seek assistance from day care centers because they are stigmatized in our society, which is why I know little about them. My father also believes it is extremely shameful to place his father under the supervision of someone else, so there should be more awareness spread about such organizations so that the lives of caregivers can be made a little easier. I believe that social media should be used to raise knowledge about how to handle such patients, how to care for the patient, and things like that.

The most prominent belief among the care givers about the cause of this disease was tension. In the case study mentioned above the respondent also explains that his grandfather had been taking stress of different things that became the cause of Alzheimer's. He also discusses how they are dealing with stigmatizing attitudes from society and how his mother was accused of performing black magic on his grandfather as a result of a lack of knowledge about this disease among the general public. Finally, the respondent discusses how and why they are embarrassed to tell people about their grandfather's mental condition because, according to the respondent, mental illness is considered taboo in our society. Respondent further stated that despite the fact that his grandfather has been suffering from the condition for the last seven years, he and his family are still uneducated to cope with it.

RELIGION

Among all subjects, religion was the most significant, with approximately all caregivers agreeing that they had sought advice from religious authorities. They believe it is not a treatment for the disease, but it does provide them with personal satisfaction.

“G mery ghar kay Qareeb masjid kay molvi shaib mujy bohat sary wazaifs bataty han taky ma un ki madad say sakoon mehsoos karayn hum aur yay wazaif bechani aur ghabrahat say bi mehfooz rakhty han”.

“Yes, I do take help from molvi sahib of my neighborhood mosque and they tell me a lot of wazaifs so to keep ourself calm and to protect from restlessness and anxiety” (Mr. Ishtiaq ahmed, 47 years old son of the patient)

“Har hafty mery ghar kay pass jo masjid ha whan say Qari shaib ik hafiz e Quran ko bejhty han taky wo telavat kary aur wo surah Rehman ki tilavat karta ha jis ki waja say humyn bohat sakoon Milta ha us ki waja say tension ka Ehsaas kam ho jata ha kuch din”.

“Every week, a Qari sahib from our neighborhood sends a hafiz e Quran who recites Surah Rehman beside grandfather. This is really beneficial to us since we feel lighter, calmer, and less stressed for a few days”. (Mr. Qasim age34)

“Ma Mazar wegera pay yakeen ni Karti magar ma har Mah mufti sahib kay pass le jati hon daam kay lia aur us say maujy bi sakoon Milta ha aur in kay Ander kuch time kay lia bi tableeli mehsoos Karti hon jase yay thory sakoon ma raty han aur gussa wegera kam karty han”.

“I don’t believe in visiting shrines however I do take him monthly to religious scholars and I notice change in his behavior he stays calm doesn’t feel anxious for some time” (Mrs. Riaz age 65)

Some caregivers believe that they are hesitant to seek assistance from religious scholars since they cannot trust anyone and rely more on medications.

“Hum inhe bohat sare muftion kay pass le kay gaye Daam wegera kay lia meri ik ristadar nay mujy ik mazar ka bataya Jahan jane say demagi Mariz theek ho jaty han kun kay shayd in pay kala jadu hoa how ya nazar lag gai ho isi waja say ma inhe us mazar pay bi le gai aur bohat sare aur mazaron pay bi le kay gai magar koi farq ni para”.

“We have taken him to many religious scholars for prayer "Daam"...one of my relatives advised me to take him to a shrine where people take their relatives for healing as she told me that this could be due to black magic or evil eye, so I took my husband there, as well as many other places, but it was ineffective”. (Mrs. Manzoor 56 years old wife)

“Hum nay kisi mufti ya Qari say madad ni li kun kay Aj Kal tu hum kisi pay Barossa ni kar saky kon sahi ha kon galat ha humay kaya Malom isi lia jab bi mery pass free time Hota ha ma kud hi surah Yaseen, surah Rehman, Charon qul parhna suru ho jati hon aur wase bi inhe bohat passand ha telavat sunna”.

“We have not taken help from any religious scholars as we cannot trust anyone and we don’t know who is right who is wrong. So that is why whenever I get free time, I recite surah Yaseen, surah Rehman, and four quls and he loves listening to the recitation.” (Mrs. Zulfiqar age 63)

“g han magar hum is pay Qaim nahi rahy kisis kism kay baba ya molvi Shaiban kay pass jane kay bajaye dawaiyan laty rahayn gay aur doctor's kay pass jayn gay”.

“Yes. But we never stick to it and would continue taking medicines and see doctor instead of visiting any kind of ‘BABAS’ or ‘MOLVI SAHIBS’.” (Mrs. Zohaib 27years old daughter of the patient)

Religion was also utilized to provide context for why family members should take responsibility for caring for a sick person.

“ ... yeh meri zimmadaari hai ke mein apne shohar ka khayaal rakhon aur Allah ne hum se shoharon ka khayaal rakhnay par inaan ka wada kya hai” .

“...it's my responsibility to take care of my husband and Allah has promised us reward for taking care of husbands.” (Mrs. Zulfiqar age 63)

“Mera manna ha agar ma in ka kayal ni rakhon gi tu mujy gunnah ho ga”.

“I believe it would be a sin if I did not look after him” (Mrs. Manzoor, age 56).

EXTERNAL HELP/CARE CENTERS

Caregivers believed that it is the religious duty to care for their relatives, thus nursing homes were mostly frowned upon. Mostly the care givers were not aware of any external help they didn’t know that if there are any care centers available in their area or not. When the researcher questioned if it was embarrassing to place a relative in a care center, approximately all of the caregivers agreed. However, a few caregivers stated that even if they wanted to seek aid from care centers, society would not allow them to do so.

“Muji ni lagta kay mery area ma koi care center ha .ma rehabilitation centers aur old homes kay bare ma tu Janti hon likn Alzheimer’s kay patient kay lia kisi day care center ka ilm nahi muji”.

“I don’t think there is any care center in my area. I know that there are many old homes and many rehabilitation centers but I don’t know if there are any day care centers for Alzheimer's patient.”
(Mrs. Zohaib 27years old daughter of the patient)

“Ma imandari say kata hon kay ma kisi bi care center say waqif nahi hon kun kay kbi taklash karnay ka moqa nahi mila magar mery ik colleague nay muji mashwara is kay ma apni ami kay lia koi attendant rakh lon kun kay humary lia in ka kayal rakhna bohat muskil ha”.

“I honestly am not aware of any care centers because never had a chance to search but one of my colleagues advised me to hire an attendant for her because it is very difficult for us to look after her...” (Mr. Ishtiaq ahmed,47 years old son of the patient)

“G han kun kay humary mashray ma log un ko bura samjty han aur un kay kilaf baat karty han joapny ristadar ko old homes ma ya nursing homes ma chor dete han aur humy kud kayal rakhna chaye apne mariz ka aur wase bi agar ma apne husband ka kayal na rakhon tu muji gunnah ho ga and ma apne husband ka kayal in nursing homes say bi behther tarikay say rakh Sakti hon”

“Yes, because in our society people talk bad about those who put their relative in old houses or nursing homes. And we should personally take care of the patient and it is a sin if I cannot take care of my husband myself. And I think I can take better care of him than these nursing homes.”
(Mrs. Riaz age 65)

MISTRUST OF EXTERNAL SUPPORT

As they were skeptical of outside support, some caregivers were unwilling to accept assistance from anyone other than their family. They didn't think the care would be as excellent as that supplied by family members.

“Patient ka kayal rakhna humari zemindari ha aur humay is mamlay ma dusron par barosa nahi kara chaye”.

“it's our responsibility to take care of our patient we should not trust others in this matter” (Mrs. Zohaib 27years old daughter of the patient)

“Mera nahi kayal kay jo care hum ghar pay karty han patient ki wase hi care centers ma Milay. Koi aur ap ka kabi bi family ki tarah kayal ni rakh sakta”.

“I don't believe that the care can be as good as family care. No other person cares for you as a family member does” (Mrs. Zulfiqar age 63)

Many caregivers displayed a sense of personal responsibility, obligation, or duty. Despite the fact that their experiences had taught us that caregiving is a hardship, nearly all of the caregivers refused to recognize it as a burden because, as Muslims, we think that it is a responsibility, and our society never accepts people who place their relatives in care of others.

BARIERS

Almost all of the caregivers agreed that hospitals should have trained personnel, and some thought there should be a distinct hospital for dementia and Alzheimer's patients. Patients and caregivers experienced barriers such as a lack of resources, a lack of skilled personnel, a lack of support centers, ignorance about the condition or day care centers, and doctors who were too busy or unavailable.

“Hum inhe daycare center ma ni bejh saky na hi hum in kay lia koi professional attendant rakgh saky han kun kay log galat batyn karyn gay agar hum nay kud in ka kayal ni Rakha”.

“We can't even put him in a day care facility or pay a professional to care for him since our family would gossip about us if we don't take care of him (Mrs. Qasim, age 34).

Jis tarha ma cheezon ko dekhta hon wo yay ha kay hospital kay staff aur doctors ko waqt ki pabandi karni chaye aur jab bi ma hospital ata hon tu muji ghanton intazar karna parta ha aur sub say bara masla yay ha kay mery walid ik jigha nahi beth saktay aur kisi bi rush wali jigha par beth kar bechani mehsoos karty han aur hospital ma Alzheimer's kay marizon kay lia ik munasib section hona chaye jis ma tarbiyat yafta staff ho.

“The way I see things is that hospital staff and the doctors should be punctual. Most of the time when I come to the hospital I have to wait for hours and the main problem is that my father cannot stay at one place and feel anxious sitting in a crowdly place and waiting for anything there should be a proper section for Alzheimer's patients and the staff there must be trained.” (Mr. Usman 24-year-old son of the patient)

“Mery kayal ma pakistan ma health care system hi ik barrier ha care Hasil karnay ma Kunn kay doctor just dawaiyan likh dete han aur wo humayn yay nahi bataty kay mariz ko gussa aye tu us say kesay nimta jaye ya jab wo dawai lene say inkar Karyn tu kaya karna chaye is lia mery kayal ma doctors ko bi train kia jaye”.

“I think the health care system in Pakistan is a barrier in receiving care as the doctors they just here to prescribe us medicines and that it they don't Counsell us about how to deal with patient when they are angry or when they don't want to take medicines what should we do about that. I think there is a need to train doctors as well.” (Mrs. Zohaib 27years old daughter of the patient)

“Mashra kisi bety ya Khandan kay sath sahi salook nahi karta agar unhe pata lag jaye kay inho nay patient ko care center ma mustakil tor par bejh dia ha”.

“The society does not treat a son or a family right if they know that they have sent someone to care center permanently” (Mrs. Qasim, age 34).

CASE STUDY

Mrs. Manzoor Hussain 56 years old has two daughters and one son it's been 6 years that her husband is suffering from this disease tells us about her experiences. My children assist me in caring for my husband. My daughter, who is a student, assists me in caring for their father; she washes his clothes and helps me prepare food for him, and one of the family members always stays beside my husband all the time because he always wants to go out and he is weak, so he cannot walk properly and needs assistance in walking; if there is no assistance, he falls and injures himself, so we have to stay with him.

My son is likewise pursuing a B.A. privately, but he is also responsible for the household. He is a very responsible child who always obeys me and helps me. He takes his father to the bathroom and helps him take a bath. He also takes his father for a walk on the weekends, not very far since Manzoor gets tired, but simply in the street outside our house. Manzoor was employed as a clerk at a government school prior to contracting this disease.

It is a disease that is frequent in the elderly because as a person age, he develops conditions such as forgetting things and becoming depressed as his brain weakens. We were not aware of this disease at first because nobody in our family had this disease before and most of us forget small things like where we put our glasses or what we were going to say or do so it was like this and we never took it seriously but slowly and gradually he started forgetting what he has eaten or has he eaten or not, date and day, he started repeating questions or is unable to do any tasks now. He can't recall anything; he just remembers his parents and doesn't remember what he ate or what we talked about a second ago.

He can't always remember our children. He is unable to perform anything on his own. He doesn't want to be in his room because he is restless, and he wants to go out all the time because now he has become weak, unable to walk normally, and has been hurt several times as a result we have to stay beside him. He urinates in his clothing at times, he can't eat properly and I have to feed him. He can be rather hostile at times, and he even hit Ahmed, my son, several times because he couldn't recognize him.

Now he can't even use his phone; he can't even do his signature; We gave him a pencil so he could sign to withdraw his pension but he can write Manzoor roughly but not correctly since he can't make ن or ظ since no one in our family has ever had this disease. It is impossible to specify the exact source of this illness. There was no such strained environment. There is tension in every home, and we cannot blame it simply on tension.

When he began forgetting things, we took him to the hospital for treatment, and the doctor told us that it was a disease and given us some medications; since then, we visit hospital for monthly checkups and medications. The doctor informed us that it is an incurable ailment and that medications can only be used to alleviate his restlessness and help him sleep. When he was alright, he was taking excellent care of us.

He was the only source of income, but he gradually began forgetting things and it became very difficult for him to do his job, so he retired from his job as three years were left before his retirement, so after retirement, his pension is the only source of income and it is very difficult for us to meet our needs. House rent, education costs, electricity and gas taxes, and medication are all unaffordable on his pension alone that is why my son is studying B. A. privately since we cannot pay any college fees, and he also needs to care for his father because my daughters are not old enough to do so. As a result, he is responsible for him the majority of the time. No, we never attempted to hide this condition. At first, no one realized he had this ailment, but as he started repeating a lot of things, our family members and Neighbours got aware but we never tried to hide his condition from anyone.

Every brain illness, in my opinion, is considered to be associated with insanity, During the early stages of his illness, he would frequently repeat his inquiry or say the same thing over and again, which our relatives would see as a joke or cause them to smile. And occasionally when we meet someone who doesn't know much about this sickness, they respond strangely or angrily when my husband asks a lot of questions over and over.

Most of my close relatives, such as my brother or my spouse's family, are upset and concerned for us because my husband was the sole source of income and handled all responsibilities. They sometimes lend us money and sometimes look after him if we need to go somewhere, but I don't go anywhere quite often. However, if there is an essential occasion that we must not miss, I either

go or send Ahmed because both of us are unable to go, hence definitely, this disease has curtailed our socialization.

We are confined to our home because he requires round-the-clock care. I'm depressed the most of the time. My son also gets depressed from time to time since he is a student and has to take responsibilities as well, so he gets worried, and as a result, he also gets irritated very quickly. Yes, we have taken him to many religious scholars for prayer "Daam"...one of my relatives advised me to take him to a shrine where people take their relatives for healing as she told me that this could be due to black magic or evil eye, so I took my husband there, as well as many other places, but it was ineffective.

No, I don't know about any day care centers and I would never take him to any day care center how can I believe any other person that he would take care of him like I do. Even though I get frustrated by taking tension of different things all the time but he is not a burden; he is my husband, and I cannot say such a thing about him. I believe it would be a sin if I did not look after him and people. There are no facilities in the hospitals; we have to wait for hours for our turn for a checkup; and there is no financial help accessible to the people since he was the sole source of income; and now my son is too young to have a career that would meet all of our demands. No one understands the difficulties that a caregiver faces the only reason is that they don't know about it and I believe that there should be a drama about this disease because people of our society like watching drama so this is the only source through which we can tell people about the problems faced by caregivers.

In the above-mentioned case study, the researcher determined that the respondent was under a huge burden of caregiving; she was also trapped in poverty, which added to her stress of caregiving. She was also wary of day care facilities and the care they offered since she believed it was her obligation to care for her husband and that failing to do so would be a sin. She also informed us that she sought advice from religious professors, but it was in vain. She also informed us about her son, who is unable to concentrate only on his education since he is also responsible for caring for his father.

CONSEQUENCES OF CAREGIVING

Caring for an Alzheimer's patient can have a detrimental impact on the caregiver's cognitive and physical well-being, typical lifespan, level of living, and financial stability. The disease can have a significant and frequently negative influence on family bonding and role performance. Alzheimer's care is demanding and necessitates time, energy, and, in many cases, physical effort on the part of the caregiver. Because the condition proceeds slowly, family members frequently give care for many years and are under a great deal of stress for extended periods of time. The persistent weariness associated with giving lengthy hours of care without breaks exacerbates the consequences of high stress levels.

“mein apna kaam sahih tareeqay se nahi kar sakta kyunkay meri wife meri ami ki dekh bhaal karne wali wahid fard hai. in par hamari baityon ki bhi zimmadaari hai is liye un ke liye akailey ami ka khayaal rakhna bohat mushkil hai is liye mein job ko kam waqt day sakta hon jis se ham financially mutasir hoye han”

“I can't do my job properly as my wife takes care of my mother all alone, she is also responsible to take care of our daughters so that is why it is very difficult for her to take care of mother alone so this is the reason why I give very less time to job and that has affected us financially” (Mr. Ishtiaq ahmed, 47 years old son of the patient).

CASE STUDY

Zubaira, a 42-year-old married lady with two children, tells us about the difficulties she faces while caring for her Alzheimer's-afflicted mother. she has just one brother, who works in Dubai, and her mother was living alone in her home because her husband died three years before she was diagnosed with this condition.

People think my mum is mad, according to her. Because my brother lives in another nation, he hired a housemaid for her. The maid was verbally and physically assaulting her. Neighbors complained about the maid, so I went and brought her to my house, and it's already been two months. I'm at a loss for what to do since I'm not sure how to care for her and control her when she

wants to go home. My children are now on summer vacation, but school will resume shortly, and I will be in big trouble.

I haven't been to the store since my mother moved in with me, so I ask my neighbor's acquaintance to get goods for me. When I need to withdraw money from the bank, I just go to the local ATM and ask my Neighbour to assist my mother for a short period of time. I don't spend much time at the ATM and quickly return home. My husband also lives abroad, and I am both a mother and a caregiver for the children. I sometimes lock her inside the home so she can't go out. she's on medication, but she's still behaving this way. Mother is constantly wishing to leave the house. She starts walking throughout the house, trying to find her way back home. She says she wants to go home, but this is not her home. She will pack her possessions and leave for home from time to time, but she will not remember how to get there. She occasionally starts looking for her 'kids.' When she goes out, I have to bring her home. When I'm pulling her back, others constantly come around. I'm embarrassed that others like looking at me, yet they don't assist me much.

When one of my children left the door open and my mother went out in the street, I saw her and when I was taking her back and mother was refusing in all of this, there was a fruit vendor standing there laughing at us, and I was so embarrassed that I started crying, and then one of my Neighbours helped me take her back home. There are relatively few individuals in my area that truly help, but others simply see what is going on and mock us. It's tough for me to take her somewhere, and I can't leave her home alone, so I never go anywhere because of this.

My Neighbor once asked me to take her to mufti sahib because she believed my mother was possessed by a Jin or that someone had done black magic on her, but I refused since I don't believe in such things and my firm belief is in Allah, so I pray for my mother and give her water to drink on which I read surah Yaseen and manzil, and I also drink that water, so I just believe in Allah that he will ease my difficulties. no, I will never put her to a care facility, as I already mentioned, I had a really horrible experience with the maid that my brother hired for her.

Even though it would be extremely difficult for me to care for her, she is my mother, and how can I send her to such a hell where instead of caring, they beat the patient? I cannot trust anyone now I have to take care of her as it's my responsibility and when we were kids my parents tried their best to fulfill our needs so it's my time now because this is a test by Allah and I want to be an obedient child and do the best I can for my mother.

CASE STUDY

Moin Aftab is 30 years old, his father passed away. He is taking care of his uncle (Chacha) Pervaiz Akhtar, with Alzheimer's who is 76 years old and does not have any children. His wife has already passed away. The patient's sister is living with him as well but she is not married and is 55 years old. Moin's two sisters have been married, one is still studying yet unmarried. His elder brother is also married, lives in England and is responsible for financially supporting the family. Moin will be sharing his experience in the upcoming paragraphs.

I am solely responsible for taking care of my uncle and running the house errands as well. My brother had also shared my responsibility when he was here. But now that he is gone the whole situation has been changed. Since my uncle is aged and is too weak to do anything by himself, I help him in daily basic activities, such as changing his clothes and diaper, changing the drips and urine bag twice a day. He barely recognizes anyone now. He had a sudden shift from anxiety to Alzheimer's, although just a year ago, he was doing good by himself. He is the eldest in the family and all the family members used to come to ask for his guidance and advise in all matters. They used to respect him a lot. Even the neighbors have always respected him. He used to possess vast religious knowledge and was very active in religious activities such as preaching. But now his personality has been completely altered. He gets agitated by the little of things. Always screams and calls for help as if there is an emergence

In this whole journey I have faced many issues, one of which is societal pressure. I have seen mixed opinions in society. People always expect that I come up with great new ideas to take care of my uncle and always demand explanations for the simple things that he does. Some people don't even have enough knowledge of the gravity of the matter. They come up with opinions like I should give him sleep pills during day, that definitely I can't do because he is a heart patient and these medicines affect the cardiac health really badly.

People have suggested me to think about care centers. But I have never for once considered it as an option because I always look at it as a way of relieving off your sufferings but putting your elder in a different and new location. It will be a sin for me to send my father-like uncle to a care center. Just a couple months ago, he used to leave the house without informing anyone and forgot

his way back home. Our family members suggested us to visit ‘Muftis’. Although we visited ‘Muftis’ several times but there has been no effective result. Ultimately, we had no resort but to restrict him to house only. As a consequence, his condition deteriorated progressively. And now he has come to a point of no return.

My social life has also been impacted by his condition because I used to go out with my friends and spend time with them, but now I have to be him all the time and all the responsibilities of the house are on my shoulders, and I am also not doing job because if I did, there would be no one to take care of uncle and all the responsibilities like taking him to the hospital, buying all the groceries, and paying the bills would be on me.

SUGGESTIONS ON HOW TO EDUCATE THE SOCIETY ABOUT THIS DISEASE.

All caregivers believed that raising public awareness regarding dementia and Alzheimer's disease was necessary, and the most preferred methods for doing so were through online/social media, television/radio, and print media.

“..asy dramas banana chaye jo kay is bemari kay bare ma hon kun kay yahan kay log dramas dekhna passand karty han tu yahi ik tariqa ha jis kay hum logon ko bata saky han un muskilat kay bare ma jo kayal rakhny walon ko uthani parti han”.

“There should be a drama about this disease because people of our society like watching drama so this is the only source through which we can tell people about the problems faced by caregivers”.
(Mrs. Manzoor age56)

“Mery kayal ma na sirf society ko balke care givers ko bi educate karna chaye ya tu newspaper ma koi column jo kay Roz Baroz naye tareeqay say logon na sirf is bemari kay bare ma Balke Baki bemariaon kay bare ma bi ko educate kia jaye”.

“In my opinion not only the society but also the care givers should be educated there should be a column in newspaper that on daily bases educate people not only about this disease but other diseases as well” (Mrs. Zohaib 27years old daughter of the patient).

“Jis tarha ma cheezon ko dekhta hon wo yay ha kay hospital kay staff aur doctors ko waqt ki pabandi karni chaye aur jab bi ma hospital ata hon tu mujy ghanton intazar karna parta ha aur sub say bara masla yay ha kay mery walid ik jigha nahi beth saky aur kisi bi rush wali jigha par beth kar bechani mehsoos karty han aur hospital ma Alzheimer’s kay marizon kay lia ik munasib section hona chaye jis ma tarbiyat yafta staff ho”.

“The way I see things is that hospital staff and the doctors should be punctual. Most of the time when I come to the hospital I have to wait for hours and the main problem is that my father cannot stay at one place and feel anxious sitting in a crowdy place and waiting for anything there should be a proper section for Alzheimer's patients and the staff there must be trained” (Mr. Usman 24-year-old son of the patient).

ADDITIONAL FACILITIES AND STAFF

Participants also expressed a need for more facilities and specialists, which should be simply accessible and low-costs.

“mery kayal ma hospitals ka system ko improve karny ki zarort ha”.

“I think the system of hospital should be improved” (Mrs. Zohaib 27years old daughter of the patient).

“ asy institutions hone chaye jo kay care givers ko train karyn kay kasay patient ka kayal rakha jaye ghar pay...”.

“ there should be such intuitions that guide care givers about how to take care of your relative at home...” (Mrs. Riaz age 65”).

“...hospital ma Alzheimer’s kay marizon kay lia ik munasib section hona chaye jis ma tarbiyat yafta staff ho”.

“There should be a proper section for Alzheimer's patients and the staff there must be trained” (Mr. Usman 24-year-old son of the patient).

DRSML QAU

CHAPTER 6

GENERAL PUBLIC PERCEPTION OF THE DISEASE

Raising Alzheimer's awareness is a global priority, according to the World Health Organization's Global Action Plan on Dementia and Alzheimer's Disease (WHO, 2017), in part because it is a critical approach to encouraging timely detection and eradicating stigma. Therefore, for this to begin, it is necessary to determine what people's views, understandings, and awareness are today in Pakistan. We know nothing about how the general population perceives Alzheimer's. As a result, the goal of this study is also to learn about the general public's perceptions about Alzheimer's disease.

Respondents had a rudimentary comprehension of Alzheimer's disease but very little knowledge of it, they recognized a number of Alzheimer's disease causes and symptoms. This condition was typically attributed to normal ageing by participants. However, several individuals incorrectly identified the cause of dementia / Alzheimer's as 'stress.' The general public doesn't really know about or identify the signs of Alzheimer's. 18 of 20 respondents do not realize the difference between the early stages of Alzheimer's disease and natural aging behavior. The symptoms are sometimes misinterpreted as being caused by black magic or evil eye. This altered participants' views of the severity of the condition. The general population frequently interprets Alzheimer's symptoms, such as insufficient self-care or incontinence, as evidence of neglect by the family or the individual himself.

To the best of respondent's knowledge, the majority of participants had never met someone with Alzheimer's disease or discussed the disease with family or friends. They have never been taught about Alzheimer's / dementia in school, colleges nor they have ever watched a TV show or movie featuring a dementia / Alzheimer's character. When the researcher inquired about the patient's duty of care, the respondents believed that getting or providing Alzheimer's care was the responsibility of either the individual with Alzheimer's or their family. Cultural beliefs affected the perception that it was the family's role to provide care. As a result, there is a greater emphasis on youngsters carrying on more responsibility.

One recurring theme in the responses was the possibility of using prayer to prevent or treat Alzheimer's. However, caregivers should not only focus on religion; they should also seek medical assistance.

Fears of getting Alzheimer's are exacerbated by a lack of knowledge, which generates stigmatizing behaviors such as avoidance or prejudice. The stigma adds to social isolation and delays in obtaining a diagnosis and support for persons with Alzheimer's, as well as their caregivers and relatives.

Stigma and misunderstanding may have a catastrophic influence on all phases of a person's Alzheimer journey, there is a need for highlighting immediate action to decrease stigma and improve knowledge throughout all sections of the community.

This chapter investigates societal Alzheimer awareness, understanding, and views. It is critical to raise public knowledge and understanding of dementia /Alzheimer's in eliminating the stigma attributed with the disease and to help people with Alzheimer and their caregivers to get adequate assistance at the right time.

The general population was interviewed to learn if they are aware about dementia and Alzheimer's disease, so we picked a sample of 20 respondents. The interviews were done in the PIMS hospital, where people were waiting for corona vaccines, as well as in the OPD sections of other departments. After collecting the data, the researcher has generated some themes which are discussed below.

KNOWLEDGE AND AWARENESS

The general population in Rawalpindi/Islamabad was uninformed about Alzheimer's and dementia, leading to stigmatizing attitudes. The public's impression of dementia is greatly impacted by a lack of knowledge about the disease. When asked what they knew about Alzheimer's, the general public was mostly clueless and these are some of the responses of the respondents.

*“Muji is bemari kay bari ma zada nahi pata just muji yay pata
ha kay age zada hone kay sath sath demag klamzor ho jata ha*

tu insan tu wo choti choti cheezayn bhoolna suru ho jata ha tu isi condition ko Alzheimer's katy han ”.

“ I don't know about the disease, but I just know with age, the brain becomes weak, then the person starts forgetting the little things, this condition is known as Alzheimer's” (Rabail Fatima, age 24, student).

“I think agar kisi ko yay masla ha tu unhe doctor's kay pass ja kay checkup Karana chaye aur consultation kay bad wo wapis apni normal Zindagi Jee sakayn”.

“I think if someone is going through it, they should consult a doctor and get themselves checked so that they can return to normal life after consultation” (Maria Tayyab, age 25, student).

“Yay bemari yadasht ki kami ka Sabab hoti ha”

“It causes memory loss,” (Abdur Rafay, age 33, employed).

Participants had a rudimentary understanding of dementia/Alzheimer's, but very little information, and they recognized a variety of causes of Alzheimer's and associated symptoms. Many individuals also misidentified the etiology of Alzheimer's as stress, not taking healthy diet etc.

“Hum healthy diet nahi lete shayad isi waja say”.

“We are not taking healthy diet that is why may be” (Zulqarnain,32, employed).

“shayad har baat ki tension lena bohat zada sochna aur akelay rehna say yay bemari ho jati ha”.

“Taking tension of the smallest thing, over thinking and remaining lonely most of the time may be causes this disease” (Abdur Rafay, age 33, employed).

BARRIERS IN RECEIVING HEALTH CARE

The general population was asked to identify potential hurdles to assessing health care for patients and caregivers. Because the respondents didn't know much about the condition, they couldn't name

any, but the majority of them said that our country's health-care system is under-resourced, which might be the most important obstacle. The second point they brought up was the economic situation and the ever-increasing rates of everything. When the researcher asked them what they thought was preventing caregivers from seeking help from daycare facilities or paid home care, they stated that our norms do not allow us to do so.

“shayad patient ke rishtadar is ka ilaaj karna chahtay hon taakay woh sehat yab ho jaye, lekin un ke paas aisa karne ke liye maali wasail ki kami ho”

“Perhaps the patient's family members want to treat him so he might recover, but they lack the financial resources to do so” (Mrs. Afrasiab, age 64, housewife).

agar meri yeh haalat ho to mein day care ki sahoalat mein nahi jana chahoon ga, to hum apne walidain ko wahan kaisay dekh satke hain? agar mein ne aisa kya to bhi mere khandan mein koi bhi is ki tareef nahi kere ga.

I would not want to be taken to a day care facility if I had this condition, so how can we see our parents being placed there? Even if I did, no one in my family would appreciate it (Mr. Umair age 34, employed).

When asked what types of stigmas they feel are linked with mental illness or this ailment, or whether they believe there is any type of stigma associated with this sickness, the general population responded in a variety of ways. We noticed that insanity is usually linked to mental illnesses.

“hum log psychological issues ko openly accept ni karty hum kosis karty han kay kisi ko pata na lagay kay humay yay masla ha mery kafi relatives han jin ko agar kaho kay ap apny bachy ko psychologist kay pass lay kay jayn ya psychiatrists kay pass le kay jayn tu wo katy han kun humara bacha koi pagal ha jo hum paglon waly doctor kay pass le kay Jayn tu isi tarh ma nay aksar logon ko yay katy hoye suna ha dill ghabtaha saans ni lene hota kun kay un kay symptoms wo depression kay hoty

han ya kisi kay agar anxiety kay han tu wo is cheez ko accept ni karty kay un ko koi psychological problem ha agy say hamesha yay reply milta ha kay nahi blood pressure ki waja say ho jata ha ya nazar lag gai ha ya kisi nay Jadu kia hoa ha.....

“We donot openly accept psychological issues and try to hide our condition from others if I ask most of my relatives to take their child to a psychologist or psychiatrists they reply why would we take our child there is our child insane why would we take our child to doctors of crazy people, similarly I have seen many people who will complain about symptoms like heart sinking, shortness of breath these symptoms indicate depression and sometime anxiety but they won't accept that it's a psychological issue and they would reply that it's because of evil eye or due to black magic.....”(Mr. Agha, age 43, teacher in a government boys school).

RESPONSIBILITY

The majority of respondents agreed that the patient's relatives should take care of the patient themselves especially their children, suggesting that they should not seek assistance from care facilities, demonstrating their lack of understanding of the problems faced by caregivers. Thirteen of the twenty respondents were of this view to not put their relative in care centers

“yeh bachon ki zimma daari hai ke woh apne maa baap ki dekh bhaal karen un kay burhaye ma , yeh hamara farz hai ke apne walidain ki dekh bhaal karen”

It is the children's responsibility to look after their mother and father in their old age. It is our duty to care for our parents (Mr. Nazar Iqbal, age 54, clerk).

“nahi, agar mera koi rishtadaar nah sirf yeh balkay Allah nah kere kisi bemari mein mubtala hota to mein kisi aur par Bharosa nah karta, mein khud is ki dekh bhaal karta”.

“No If one of my relatives was suffering from not only this but any disease God forbid, I wouldn't have trusted someone else I would have taken care of him myself” (Mr. Mudassir, age 26, student).

“Mere khayal mein inhen khud mareez ka khayal rakhna chahiye kyunkay hum kisi aur par Bharosa nahi kar satke. kyunkay hamari society mein is qisam kay care centers hain kay mujhe yaqeen hai ke woh is baat se bhi waaqif nahi hain ke aisay patients se kaisay nimta jaye”

“I think they themselves should take care of the patient as we cannot trust anyone else. Because these kind of care centers in our society that I believe they are also not much aware of how to deal with such patient.” (Abdur Rafay, age 33, employed)

RELIGION

Respondents were asked what do they think that should the relative of the patient take help from the religious scholars? they told that if they find the religious scholar to be trust worthy then they should take help from the religious scholars, some told that medical help should be focused on. One recurrent topic among responses was that prayer could be used to prevent or treat dementia.

“haan, agar woh shakhs (mazhabi scholar) koi Aisa shakhs hai jis par hum Bharosa kar satke hain aur woh deen ka ilm rakhnay wala shakhs hai to agar woh mareez ko aaraam pohanchanay mein madad kar sakta hai aur lawahiqaen ko kisi qisam ke wazaif bta kar khud ko pursukoon karne mein madad kar sakta hai. un ulama se zaroor madad leni chahiye”

“Yes, if that person (religious scholar) is someone whom we can trust and he is a person with knowledge of deen so if he can help in relaxing the patient in in helping the relatives to calm

themselves by telling them some kind of wazaifs so we should definitely take help from these scholars” (Mr. Nazar Iqbal, age 54, clerk).

*“Agar koi sirf zehni Sukoon ki khatir chahta hai to kyun nahi
lekin clinical help bohat zaroori hai” .*

“If someone wants just for the sake of mind peace then why not but clinical help is very important” (Mr. Agha, age 43, teacher in a government boys' school).

SUGGESTIONS

The care givers and also the members of the genral public in this research recognized the need to promote Alzheimer's awareness and the most preferred methods for doing so were through online/social media, television/radio, and print media.

“Television and social media can be used to create awareness about the disease among youth as well as general public”, “By conducting seminars start giving free therapies, mount posters everywhere, show acceptance and be all ears”, “Through public institutions educational institutions and ads”.

Clinical components of Alzheimer care, such as diagnosis, evaluation, and treatment, as well as excellent long-term care, should be addressed in Alzheimer care guidelines. They should also offer information on any legal or ethical problems that may jeopardies quality care Hence the need for diagnostic and needs-based assessment instruction in basic clinical, nursing, and counseling curricula, as well as a shift away from the current focus on easy effective treatments and toward long-term care and serious disease treatment. Given the vulnerability of many older individuals with persistent diseases, there is also a need for instruction in outdoor care, as well as monitoring and evaluating patients in their houses. Small community homes should be considered as an alternative to standard care home kinds of residential care.

Psychiatrists, psychologists, and neurologists should provide guidelines to support the physical and mental functioning and well-being of the caregiver and care receiver for as long as feasible.

Critical role of carers in both sustaining the care recipient's quality of life and offering the most cost-effective model of long-term care, suitable and accessible support structures are essential. They should contain advice on how to provide social engagement and recreational activities, mental functioning and therapy, awareness of psychological and behavioral change and its reasons, and safe and positive learning locations. Understanding the characteristics and duration of the disease, as well as what resources are available to families, are all knowledge needed, as is training in how to care for people with the disease and how to avoid and deal with behavioral issues. Counselling and long-term support, caregiver conferences, and supportive services are some of the ways for assisting carers. Caregivers also require financial aid in order to accomplish their duties properly and sustain them over time.

Also, there is a scarcity of significant social science research in Pakistan, particularly in Rawalpindi/Islamabad, and more work needs to be done to assess people's knowledge, views, and opinions about Alzheimer's in order to advocate for the most beneficial plans and practices for raising awareness and providing support services to people with Alzheimer's and their caregivers.

CHAPTER 7

SUMMARY AND CONCLUSIONS

SUMMARY

The current study sought to learn about caregivers' coping mechanisms and general public understanding of Alzheimer's disease, as well as the stigmas associated with the condition and care facilities. The first chapter of this study is the orientation of the study it outlines the relevance of the study, which is to minimize society's stigmatizing attitude toward this condition by raising society's awareness. The aims of the study are also described there which included the coping mechanism of the care givers of Alzheimer's patients, society's awareness and attitudes and thirdly the stigmas attached with the mental illness and specifically Alzheimer's and dementia. Second, the research intends to assist the government in developing policies about this disease, as there are very few facilities available to the people in our society.

The next chapter is about the literature review which help the reader to understand the disease and caregivers' strains from all over the world and also about the previous works done on the disease. moving on to the next chapter it is about the area profile as the research is done in the premises of the PIMS hospital so its location, climate, region etc. is discussed in that chapter.

Furthermore, the next chapter is about the qualitative methodology in the present research the researcher has used inductive approach and purposive sampling technique has been used the research techniques which are used in this research are the participant observation key informant rapport building and the tools used are interview guide, In depth interviews, field notes photography etc. The following two chapters contain the data analysis of the research, and the researcher has examined the research findings as well as transcribed the interviews and case studies. The major findings of the research are that Alzheimer's disease is devastating for those who suffer from it as well as their loved ones. The stigmatizing ideas about Alzheimer's disease should be changed in society. The possibility of using prayer to prevent or treat Alzheimer's disease was a popular topic in Pakistan. While teaching children to care for their parents in their old age

and husbands when they are sick is wonderful, it misses the complexity of Alzheimer's. Many of those interviewed had almost no knowledge about dementia or Alzheimer's disease. Caregivers believed that raising Alzheimer's awareness in Pakistan through social media, television, and radio was essential. A lack of faith in outside aid was a barrier to receiving help.

CONCLUSION

In Pakistan, there is a dearth of understanding and awareness of Alzheimer's disease, which leads to stigma and barriers to examination and care. Caregivers, families, and society are all affected by the condition on biological, cognitive, and economic levels. It may also have an adverse effect on the lives of others who are socially connected to the affected individual. It not only leads to errors about prognosis and treatment, but it also has an influence on how individuals perceive their responsibilities to care for others. The researcher believes that the most major hurdle is a lack of understanding about the condition among caregivers and the general public.

There is a common mentality in Pakistan that we constantly attach a stigma to mental health, which is why we avoid discussing it in public. This study concludes that depending on caregivers without first analyzing their capacity to provide care may result in a difficult and very detrimental environment for both the caregiver and the care receiver.

The care givers as well as the general public should be properly informed so that if they come across someone looking for or trying to ask for his house, they will know what to do. They should not only offer instructions, but should also ask the most essential question, "What day of the week and month is it?" If the man responds accurately, it indicates that he will be permitted to return home. If not, they should take the individual to the nearby police station or inform using the patient's phone, if one is accessible, and then wait for his caregivers to arrive.

The government must guarantee a wide range of support services, such as respite care and expert assistance. there is a need to pay more attention to noncommunicable diseases, particularly mental health, at the policy and program levels, according to the World Health Organization. Health workers should be better trained, more organized and more readily available to individuals is need, (WHO)

CHAPTER 8

BIBLIOGRAPHY

- Aurooj, A., & Mahmood, Z. (2022). Subjective Experiences of Alzheimer's Disease in the Pakistani Cultural Context: An Exploratory Study. *Journal of Religion and Health*, 61(1), 125-138.
- Ahmad, A., Khatri, I., Siddiqui, M., Khan, N., Kamal, S., & Mehboob, N. (2011). P4-181: Dementia in Pakistan: initial results from our registry at a tertiary care hospital. *Alzheimer's & Dementia*, 7, S767-S767.
- Boling, T. E. (1990). Awareness of Alzheimer's disease: A study in three rural Ohio counties. *American Journal of Alzheimer's Care and Related Disorders & Research*, 5(6), 32-36.
- Ballard, E. L., Nash, F., Raiford, K., & Harrell, L. E. (1993). Recruitment of black elderly for clinical research studies of dementia: the CERAD experience. *The Gerontologist*, 33(4), 561-565.
- Barker, R. L. (1995). *The social work dictionary* (3rd ed.). Washington, DC: NASW Press.
- Byrne, P. (2000). Stigma of mental illness and ways of diminishing it. *Advances in Psychiatric treatment*, 6(1), 65-72.
- Byrne, P. (1997). Psychiatric stigma: past, passing and to come. *Journal of the royal society of medicine*, 90(11), 618-621.
- Cipriani, G., Danti, S., Picchi, L., Nuti, A., & Fiorino, M. D. (2020). Daily functioning and dementia. *Dementia & Neuropsychologia*, 14, 93-102.
- Creswell, J. W., & Creswell, J. D. (2017). *Research design: Qualitative, quantitative, and mixed methods approaches*. Sage publications.
- Cankurtaran, M., Halil, M., Ulger, Z., Dagli, N., Yavuz, B. B., Karaca, B., & Ariogul, S. (2006). Influence of medical education on students' attitudes towards the elderly. *Journal of the national medical association*, 98(9), 1518.
- Chang, K. H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of advanced nursing*, 53(4), 435-443.
- Castro, D. M., Dillon, C., Machnicki, G., & Allegri, R. F. (2010). The economic cost of Alzheimer's disease: Family or public-health burden? *Dementia & Neuropsychologia*, 4, 262-267.
- Downs, M. & Bowers, B. (Eds)(2010) *Excellence in Dementia Care: Research into Practice*. Maidenhead: Open University Press

Ecklund-Johnson, E., & Torres, I. (2005). Unawareness of deficits in Alzheimer's disease and other dementias: operational definitions and empirical findings. *Neuropsychology Review*, 15(3), 147-166.

Elliott, G. C., Ziegler, H. L., Altman, B. M., & Scott, D. R. (1982). Understanding stigma: Dimensions of deviance and coping. *Deviant behavior*, 3(3), 275-300.

Ferri, C. P., & Jacob, K. S. (2017). Dementia in low-income and middle-income countries: different realities mandate tailored solutions. *PLoS medicine*, 14(3), e1002271.

Fauth, E. B., & Gibbons, A. (2014). Which behavioral and psychological symptoms of dementia are the most problematic? Variability by prevalence, intensity, distress ratings, and associations with caregiver depressive symptoms. *International journal of geriatric psychiatry*, 29(3), 263-271.

Gatz, M., & Pearson, C. G. (1988). Ageism revised and the provision of psychological services. *American Psychologist*, 43(3), 184-188

Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.

Gureje, O. Y. E., Lasebikan, V. O., Ephraim-Oluwanuga, O., Olley, B. O., & Kola, L. (2005). Community study of knowledge of and attitude to mental illness in Nigeria. *The British Journal of Psychiatry*, 186(5), 436-441.

Hossain, M., Crossland, J., Stores, R., Dewey, A., & Hakak, Y. (2020). Awareness and understanding of dementia in South Asians: A synthesis of qualitative evidence. *Dementia*, 19(5), 1441-1473.

Hugo, C. J., Boshoff, D. E., Traut, A., Zungu-Dirwayi, N., & Stein, D. J. (2003). Community attitudes toward and knowledge of mental illness in South Africa. *Social psychiatry and psychiatric epidemiology*, 38(12), 715-719.

Hyder, S. E., Gabbard, G. O., & Schneider, I. (1991). Homicidal maniacs and narcissistic parasites: stigmatization of mentally ill persons in the movies. *Psychiatric Services*, 42(10), 1044-1048.

Huxley, P. (1993). Location and stigma: A survey of community attitudes to mental illness-Part 1. Enlightenment and stigma. *Journal of Mental Health*, 2(1), 73-80.

Kessler, R. C., Berglund, P. A., Bruce, M. L., Koch, J. R., Laska, E. M., Leaf, P. J., ... & Wang, P. S. (2001). The prevalence and correlates of untreated serious mental illness. *Health services research*, 36(6 Pt 1), 987.

Kane, M. N. (1999). Factors affecting social work students' willingness to work with elders with Alzheimer's disease. *Journal of Social Work Education*, 35(1), 71-85.

Kawulich, B. B. (2015). Chapter 12: Collecting data through observation. University of West Georgia.

Kaplan, H., & Sadock, B. (1998). Synopsis of psychiatry 8th ed Philadelphia: William. Wilkins company.

Khan, Y. H., Zaman Khan, M., & Najam, S. (2017). Dementia survey among attendees of a dementia awareness event in Karachi, Pakistan. *Pakistan Journal of Neurological Sciences (PJNS)*, 12(4), 34-41.

Lin, S. Y., & Lewis, F. M. (2015). Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future. *The Gerontologist*, 55(2), 237-244.

Laws, G. (1995). Understanding ageism: Lessons from feminism and postmodernism. *The Gerontologist*, 35(1), 112-118.

Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Reexamining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of cross-cultural gerontology*, 23(3), 283-299.

Leroi, I., Chaudhry, N., Daniel, A., Dunne, R., Eman, S., Farina, N., ... & Wasay, M. (2019). A roadmap to develop dementia research capacity and capability in Pakistan: a model for low-and middle-income countries. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 5, 939-952.

Mirotnik, J. (1998). Epidemiological findings on selected psychiatric disorders in the general population. *Adversity, stress, and psychopathology*, 235-284.

Neuman, W. L. (2014). *Social Research Methods: Qualitative and Quantitative Approaches* (seventh ed.).

Punch, K.F. (1998) *Introduction to Social Research: Quantitative and Qualitative Approaches*. Sage, London. Methodology

Prince, M. (2004). Care arrangements for people with dementia in developing countries. *International journal of geriatric psychiatry*.

Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family practice*, 19(2), 135-139.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *The American journal of geriatric psychiatry*, 12(3), 240-249.

Schneck, M. K., & Reisberg, B. Ferris. SH (1982): An overview of current concepts of Alzheimer's disease. *Am. J. Psychiatry*, 139, I65

Thomas, D. R. (2006). *A General Inductive Approach for Analyzing Qualitative Evaluation Data*.

World Health Organization. (2012). *Dementia: a public health priority*. World Health Organization.

Waqas, A., Zubair, M., Ghulam, H., Ullah, M. W., & Tariq, M. Z. (2014). Public stigma associated with mental illnesses in Pakistani university students: a cross sectional survey. *PeerJ*, 2, e698.

Werner, P., Mittelman, M. S., Goldstein, D., & Heinik, J. (2012). Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist*, 52(1), 89-97.

Yang, L. H., Kleinman, A., Link, B. G., Phelan, J. C., Lee, S., & Good, B. (2007). Culture and stigma: Adding moral experience to stigma theory. *Social science & medicine*, 64(7), 1524-1535.

Yektatalab, S., Sharif, F., Kaveh, M. H., Khoshknab, M. F., & Petramfar, P. (2013). Living with and caring for patients with Alzheimer's disease in nursing homes. *Journal of caring sciences*, 2(3), 187.

Zaidi, A., Stefanoni, S., & Khalil, H. (2019). *Moving from the Margins: Promoting the Rights of Older Persons in Pakistan*. Policy Brief. British Council Islamabad and HelpAge Pakistan.

Zaidi, A., Willis, R., Farina, N., Balouch, S., Jafri, H., Ahmed, I., ... & Jaffri, R. (2019). *Understanding, beliefs and treatment of dementia in Pakistan*.

Zaidi, A. (2013). *Global Age Watch Index (2013). Purpose, Methodology and Results*. Report prepared for HelpAge International, Centre for Research on Ageing, University of Southampton.

Zaidi, A., Stefanoni, S. and Khalil, H. (2019). *Moving from the Margins: Promoting the Rights of Older Persons in Pakistan*. Policy Brief. British Council Islamabad and HelpAge Pakistan.

Zaidi, A. (2016). In Pakistan, old age means being in the throes of joblessness, poor health, loss of control over life. *The News International*, Pakistan.

Zaidi, A., Stefanoni, S., & Khalil, H. (2019). *Moving from the Margins: Promoting the Rights of Older Persons in Pakistan*. Policy Brief. British Council Islamabad and HelpAge Pakistan.

<https://www.nia.nih.gov/health/what-alzheimers-disease>

<https://www.alzint.org/about/dementia-facts-figures/dementia-statistics>

<https://pill.org.pk/2018>

[http://alz.org.pk/\(2019\)](http://alz.org.pk/(2019))

DRSML QAU

ANNEXURE

GLOSSARY

| | |
|--------------------|---|
| ALZHMERS | Alzheimer's disease is a progressive brain ailment that gradually deteriorates cognitive and memory abilities, as well as the capacity to do even the most basic functions. |
| ADI | Alzheimer's disease international |
| NIA | National institute of Aging |
| SPMI | Severe and persistent mental illness. |
| CFCGs | Chinese family care givers. |
| PILL | Pakistan institute of living and learning. |
| PWD | People with dementia. |
| DEMENTIA | Dementia is defined as a loss of mental function, which includes thinking, memory, and understanding. |
| WHO | The World Health Organization is a United Nations specialized organization in charge of international public health. |
| LATE ONSET | Referring to a medical problem that develops later in life |
| EARLY ONSET | Referring to a medical problem that develops earlier in life Specifically in regard to other persons who have the condition. |
| OPD | Out Patient Department. |
| PA | Personal assistant. |
| TAT | Thematic analysis technique. |

INTERVIEW GUIDE

Semi-structured interview guide for caregivers of people with dementia and for people with no experience of dementia.

INTERVIEW GUIDE FOR CARE GIVERS

1. What is your name, age, and relation with the patient?
2. How many family members are in your home?
3. Who is responsible of taking care of the patient?
4. Have you divided responsibilities of the patient among all family members?
5. Since how long is he suffering from this disease?
6. What do you think your relative is suffering from?
7. Do you think it's a disease or it's just a normal process of aging?
8. What were the initial symptoms you noticed when this problem started?
9. What more symptoms of this condition are you able to identify the lateral or present now?
10. Were you aware of this disease before your relative was diagnosed of this disease?
11. If you were not aware of this disease, how did you get to know this disease?
12. What do you think is the reason behind this disease or what is the cause of this disease?
13. Did you ever tried to hide this disease form anyone?
14. Do you think memory and psychological issues are being stigmatized in Pakistani society?
15. Have you ever felt that people make fun of your relative when he /she is unable to do even the simplest tasks?
16. What were the reaction of your relatives and people around you when they knew that he or she is suffering from this disease?
17. Besides medical help have you ever taken help from any religious scholars?
18. If you have taken help from any religious scholars than did you find it helpful?
19. Do you think that religion is playing its part in dealing with the disease? if yes how?

20. Have you ever felt depressed while taking care of your relative?
21. Have you ever felt any burden taking care of your relative?
22. Are you aware of any care center in this area?
23. Have you ever approached any care center?
24. What kind of experience you had there?
25. What are your reviews on care centers?
26. Do you think there is a need of more care center in this society?
27. Do you think it's shameful to put your relative inside a nursing home?
28. Are there any barriers to approach any kind of support or medical care?
29. Do you think society is well aware of this disease?
30. Can you give any suggestion on how can we spread awareness of this disease?

INTERVIEW GUIDE FOR GENERAL PUBLIC

31. What is your name?
32. How old are you?
33. What do you think mental illness is?
34. Do you know there is a disease called Alzheimer's?
35. If yes, then what do you know about this disease?
36. How do you know about this disease?
37. Have you ever experienced meeting with such patient?
38. Have you ever heard about any stigma attached with mental illness?
39. What are your views on this disease and what do you think is the reason behind this disease?
40. Do you think that there is a need to educate people about mental illness?
41. How do you think that general public should be educated about mental illness and specifically this disease?
42. If you find such patient lost, will you help them if yes how?
43. How do you think we can help the care givers in reducing their stress?
44. Do you think it's a disease or just simple process of aging?
45. Do you think this disease is caused by black magic?

46. Do you think people suffering from this disease should get help from any religious scholars?
47. What are your views on care centers in our society?
48. Do you think that people should get help from nursing homes?
49. How do you think we should change the views of our society about nursing homes?
50. What measures and precautions do you think should be taken as per society is concerned for the safety and care of the patient?

DRSML QAU