

**Exploring the experiences of South African Hindu families caring for an individual
diagnosed with Dementia of the Alzheimer's Type**

by

Liashna Pillay

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SUPERVISOR: Professor. C. Laidlaw

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Declaration

University of South Africa

Faculty of Psychology

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NAME: Liashna Pillay

STUDENT NUMBER: **55901603**

SIGNATURE: 

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Abstract

The aim of this study was to identify, explore, and develop an understanding into the lives of Hindu families who live with and provide informal care for a Dementia of Alzheimer's type patient that is a relative, residing within South Africa. This study provides literature and data for Hindu families, in order to understand their experiences. The study was adapted according to Kenneth Gergen's Social Constructionist Theory and Urie Bronfenbrenner's Ecological System's Theory model, which was utilised within the study to explore the systemic impact of Hinduism on Dementia of Alzheimer's type patients. The study adopted a purposive-sampling method to recruit a homogenous sample set of eight participants for the study. The researcher conducted face-to-face and virtual interviews using a semi-structured approach to obtain data. The data obtained from the study was analysed using Braun and Clarke's Thematic Analysis in order to identify reoccurring themes across the literature. Findings reveal that caregiving involves significant emotional, physical, and psychological challenges, including role reversals and lifestyle adjustments. Hindu beliefs, such as karma, reincarnation, and filial duty, shaped how caregivers understood the disorder and approached care, serving as both a moral obligation and coping mechanism. Participants also reported caregiver burnout, social isolation, and barriers to formal healthcare. The study highlights the influence of cultural and spiritual factors on Dementia care and highlights the need for targeted support and culturally sensitive interventions for informal caregivers.

Key words: Dementia of Alzheimer's type, ecological system's theory, Hinduism, purposive-sampling method, social constructionist theory, South Africa, systemic, thematic analysis

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Chapter 1: Introduction

1.1 Introduction

The following chapter aims to provide the reader with an overview of the research study. Firstly, the context of the research study is provided in order to orientate the reader to the study. With specific focus on the concept of 'ageing' and 'Dementia' in relation to the research problem relating to the study, moreso, from a South African context. In addition, the significance of why the study is important for the healthcare field, specifically, healthcare workers such as Psychologists, Psychiatrists, and other healthcare workers who may encounter a Dementia patient that practices within the Hindu religion.

The aims and objectives of the study will be briefly discussed with regards to the gap that this research study aimed to fill. Lastly, a brief overview of each chapter will be provided.

1.2 Background

Ageing is a normal process, whereby, as individual's age there are specific changes that occur within one's body (Langa, 2018). More specifically, these changes occur within the brain which often leads to various impairments in one's memory and thinking abilities (Langa, 2018).

Albeit these changes are considered as being 'a normal part of the ageing process', the dysfunction and impairments that it leads to differs amongst individuals, especially those who punctuate from a specific religious or cultural epistemology. Despite this, it is important to mention that ageing does not automatically equate to Dementia or symptoms of the disorder (Langa 2018). Therefore, it remains pivotal to distinguish between normal ageing processes and processes that cause dysfunction in one's daily living.

Apart from the disorder being misunderstood as a normal ageing process, there are various factors that contribute to the way that the disorder is perceived and treated (Boroschowits,

2011). Factors such as: religious beliefs, psychoeducation, awareness of the disorder, and cultural beliefs to name a few (Boroschowits, 2011). These factors often lead to stigmatisation and how the disorder is understood and treated by the individual's family and/or informal caregiver.

The current study focuses specifically on the way that Dementia of Alzheimer's type is understood and conceptualised amongst a small percentage of the Hindu population who reside in Gauteng, South Africa. Current statistics are not representative of the statistics surrounding how many Hindu South Africans are diagnosed with the neurodegenerative disorder, which may further perpetuate why the neurodegenerative disorder is misunderstood by family members and the larger Hindu community residing in South Africa, who provide informal caregiving for their diagnosed relative.

In addition to understanding ageing and how that affects an individual, it is also important to consider the socioeconomic development of a country as an important factor to be aware of when considering the way in which a population ages (Heese, 2015). Other factors such as age, religion, education as well as ethnicity are also considerable when looking at how a population ages (Heese, 2015). South Africa, located at the southern tip of Africa, consistently experiences an annual positive growth in population with the current population being 60.6 million people (Department of Statistics South Africa, 2022).

Amongst the 60.6 million citizens, there are 5.59 million individuals who are 60 years old or older, which makes up 9.2% of the South African population. According to Combrinck et al. (2017) the World Health Alzheimer's Report reported that approximately 187 000 people over the age of 60 years old, in South Africa, would be living with Dementia. In the same report compiled in 2017, this approximation was predicted to increase to 250 000 people by the year 2030 (Combrinck et al., 2017).

However, in a study conducted by Albanese et al. (2023) an estimated amount of less than 450 000 individuals within South Africa have Dementia, with only 2.5% of these individuals having been diagnosed previously. The data that was reported by Albanese et al. (2023), focused on observing the low and middle-income population within South Africa, whereby, minimal observations were placed on factors such as ethnicity, religion, and education. In light of this, Albanese et al. (2023) have reported that there is a need for local data regarding the prevalence of Dementia.

Albanese et al. (2023) identified a lack of culturally specific data amongst Dementia diagnosed individuals in South Africa. Therefore, the current study addresses this gap by focusing on a specific cultural and religious group, Hindu families caring for a Dementia diagnosed relative in Gauteng. The study addresses the nuance in religious and cultural data highlighted by Albanese et al. (2023). Instead of focusing only on the prevalence of Dementia, the current study explores how religious beliefs affect informal caregiving experiences, provided by family members of a Dementia diagnosed relative from a Hindu background.

Thus, the current study provides a deeper understanding of the religious as well as the cultural factors that affect caregiving practices within South African Hindu communities. However, there is still a need for future studies to focus on the widespread of Dementia within South Africa and amongst the diverse cultural groups.

1.3 Problem Statement

The problem that this study aimed to explore is Hinduism alongside the medical model in relation to Hindu devotees living in South Africa, who may experience a family member who has received a diagnosis of Dementia of Alzheimer's type. As an individual or their family's faith does not necessarily subscribe to the medical model. By exploring how Hindu families experience living with a Dementia of Alzheimer's type patient, the study

encapsulated the various factors that contribute to appropriate caregiving for an individual who has been diagnosed with Dementia of Alzheimer's type.

Within the philosophical beliefs of practicing Hindu devotees, individuals who are diagnosed with Dementia of any type, present with symptoms such as delirium, hallucinations for example, which are attributed to the diagnosed individual's past life actions or are seen as part of their 'kismet' which means destiny (Bala et al., 2016). These beliefs which are salient in the Hindu culture, potentially encourage stigmatisation to occur within the community (Gowda & Guruprasad, 2024).

As a result, based on available literature from India reported in the preliminary literature review, it is evident that the experience of being stigmatised leads to the diagnosed individual being marginalised from society which leads to the lack of seeking appropriate treatment (Siette et al., 2023).

Furthermore, the family of the diagnosed individual is also isolated from their respective community due to the fact that within the philosophy of Hinduism being associated with either an individual who has a mental health illness or a disorder, would increase the other persons chances of experiencing their own mental health problems (Laher & Padayachee, 2014). Thus, both the family members who provide care for the diagnosed individual as well as the diagnosed patient – experience stress, loneliness, and fear (Brodaty, 2009; Nieuwenhuis, 2020).

In line with this, the way that individuals diagnosed with Dementia of Alzheimer's type understand and make sense of their illness is influenced by their cultural values and belief systems (Sayegh & Knight, 2013). This is because these cultural values and beliefs often shape how Dementia of Alzheimer's type is understood, as well as influence the help-seeking behaviours of affected individuals (Sayegh & Knight, 2013).

Therefore, by gaining an understanding of cultural conceptions of Dementia of Alzheimer's type, particularly within Hinduism, healthcare workers are better able to provide culturally sensitive care, which in turn influences how diagnosed individuals interpret and respond to their diagnosis (Sayegh & Knight, 2013). Additionally, this understanding supports families in providing more appropriate caregiving and ultimately shapes how the diagnosed individual engages with treatment but moreso, reduces the stigma around the disorder (Shatnawi et al., 2023).

Whilst there are a number of practicing Hindu devotees in South Africa, the increasing prevalence of Dementia of Alzheimer's type, is a concern. More so, the lack of availability of research on Dementia of Alzheimer's type experienced by specific religious groups within South Africa, is minimal.

1.4 Study Aims and Objectives

1.4.1 Research Question

Mason (2002) suggests that the research question, formulates the backbone of a qualitative research study. It is described as the "phenomenon investigated" (Durrheim et al., 2006). The research question for this qualitative research study, refers to the main question that the study will explore. Due to the open-ended nature of a qualitative research question, participants are able to share their thoughts, feelings, and experiences regarding the investigated subject.

The main question that this study aimed to explore is:

1.4.1.1 What are the experiences of Hindu families caring for and living with a Dementia of Alzheimer's type patient?

In addition, the following questions are secondary and aimed to further explore the way that Dementia is perceived amongst Hindus:

1.4.1.2 How do Hindu families perceive and conceptualise Dementia?

1.4.1.3 How does Hinduism contribute to the stigmatisation of Dementia?

1.4.1.4 How does Hinduism affect the treatment and/or care of a relative with Dementia?

1.4.2 Research Objectives

In order to achieve the aim of this research study, which is to explore the experiences of South African Hindu families living with and caring for an individual who has been diagnosed with Dementia of Alzheimer's type, the following research objectives were formulated as follows:

The primary objective of this research study was to engage in in-depth discussions with individuals from Hindu families, living with a Dementia of Alzheimer's type relative, in order to gain a detailed understanding of their experiences. In addition, the researcher intended to explore the challenges of the religious and cultural meaning of Dementia from a Hinduist perspective.

Furthermore, the researcher explored the meaning of Mental Health within the philosophy of Hinduism in relation to Mental Health from a Western Perspective. By doing this, a contrast of how people punctuate their experiences was documented in order to distinguish the different ways that the neurodegenerative disorder of Dementia of Alzheimer's type is perceived and understood.

1.5 Significance of the Study

Understanding the way the neurodegenerative disorder of Dementia of Alzheimer's type is conceptualised across cultural and religious groups, not only improves the treatment of the neurocognitive disorder for the individual who has been diagnosed, but also improves the outcome of those who treat the disorder and more specifically those who care for an individual diagnosed with the disorder.

The findings obtained after the researcher conducted this study, not only provide the subjective experiences of Hindu families, but also provide insight into how Hinduism shapes the way that Dementia from a general perspective as well as Dementia of Alzheimer's type is understood.

The concepts of ageing and Dementia have a significant association with the concept of stigma in many cultures. Despite this association being something that is accepted and known amongst many cultural groups, there is no understanding as to why this stigma ceases to exist (Rewerska-Juško & Rejdak, 2020). Moreover, questions pertaining to why there is a known acceptance amongst these cultures to avoid speaking about the neurodegenerative disorder is not known.

As a result, not only does the stigmatisation affect the treatment process for the diagnosed individual – but it also impinges their right to being treated with dignity, their right to life, and the quality of that life. The researcher, who has observed the impact of Dementia within the Hindu community, has first-hand experience of how these religious beliefs have a significant impact upon the individual diagnosed with Dementia of Alzheimer's type, as well as their family.

Therefore, this study remains beneficial not only for patients diagnosed with Dementia of Alzheimer's type, who are Hindu, to receive the adequate treatment and care, but it also highlights whether psychoeducation within the broader Hindu community is necessary and/or beneficial.

To reduce the stigmatisation that marginalises Dementia patients within the broader Hindu community, providing psychoeducation in the form of workshops on how to care for a patient with Dementia of Alzheimer's type as well as how to identify the signs and symptoms of

Dementia of Alzheimer's type has been proposed as a prominent aspect to consider within the healthcare field (Oliviera & Forlenza, 2019).

Furthermore, this research study aims to potentially serve as a foundation and aid policymakers in South Africa to establish and/or improve policies around the caregiving of Dementia patients, moreover, the rights of those diagnosed with the disorder in order to improve their quality of life as well as the experiences of those who provide caregiving to the affected patient.

1.6 Chapter Overview

Chapter two provides a literature review on preceding literature pertaining to Dementia of Alzheimer's type from other countries, highlighting the minimal literature available in South Africa, as only one research study was conducted and utilised in this chapter. Focusing on the definition of the disorder, the Diagnostic Statistical Manual of Mental Health Disorders, Fifth Edition Text Revision (DSM-5 TR) diagnostic criteria of Dementia of Alzheimer's type are outlined and the different types of the Dementia are distinguished in order to understand that Dementia is an 'umbrella term' for various neurodegenerative disorders (American Psychiatric Association, 2022).

Furthermore, Hinduism is extensively explored with regards to its history, as well as the various beliefs and practices within the religion. An in-depth discussion on the way Dementia of Alzheimer's type is socially constructed within the religious philosophy, and understood within the Indian Psychology paradigm as well as how the disorder affects caregivers is further discussed.

Chapter three focuses on the methodology of the research study. The epistemology of Social Constructionism (Gergen, 1985), and theoretical framework of the research study, the Bioecological model (Bronfenbrenner, 1994) are adapted to the study and are also discussed

in relation to the study. Linking this to the Family Systems theory (Bowen, 1978). A qualitative research approach was adopted utilising semi-structured interviews to understand the subjective experiences of individuals from Hindu families, living with a Dementia of Alzheimer's type relative within the South African context.

Chapter four is a thematic analysis of the transcribed interviews enabled an-in depth discussion of the findings that were obtained after the researcher conducted the semi-structured interviews with the participants (Braun & Clarke, 2013). Further analysis of the findings in relation to the overall study is provided. As such, the findings are connected to the existing literature in order to explore the connection between the findings of the current study and the research questions posed.

Chapter five concludes the current study by presenting the key findings of the study and their interpretation. Further discussion on the study's strengths as well as its limitations are provided. Specific focus pertaining to the study's implications as well as what future research directions researchers should consider, is discussed.

Chapter 2: Literature Review

2.1 Operational Definitions of Key Concepts

The following chapter focuses on orientating the reader around the various religious and medical terminology that underpin this study in relation to Dementia. As a result of the fact that many participants narratives are shaped by a constellation of varying beliefs and values which shape their medical experience of Dementia, it remains significant to understand the various terms that carry specific meaning. By defining the following terms, it will provide a skeleton for how the researcher and participants may have established a sense of meaning making using these terms interchangeably. In addition, a literature review outlining preceding and current research into both Dementia and Hinduism is presented in order to situate the study within the broader scholarly and academic discourse of Dementia and Hinduism.

2.1.1 Religious Terms

Astrology: the study of celestial objects (stars, sun, moon, and planets) and how they move and are positioned in order to derive the meaning of human events (Laher & Padayachee, 2014).

Hindu/Hinduism: A dominant religion in India that is described as “worshipping many gods” (Hewamanage & Sang, 2015, p. 18). The supreme within the religion is a being known as ‘Brahma’ who is known as the creator. The core aspect of Hinduism is characterised by complex beliefs and values i.e., the belief in reincarnation. Furthermore, the religion is maintained by various caste systems which consist of different groups of Hindu devotees that are hierarchically organised according to one’s social status and demographic location. These caste systems determine an individual’s access to resources and how they are perceived within the community (Laher & Padayachee, 2014).

Karma: Hindu belief that every action and decision has a consequence on a person's life.

The consequence is either good or bad, depending on their action or decision (Tull, 2004).

Reincarnation: a religious belief that after death, a person's soul or spirit begins a new life in a new body either animal or human depending on the person's actions in their previous life (Nagarai et al., 2013).

Stigma: a form of devaluing and shaming another person due to certain characteristics they possess, which leads to the individual being marginalised or isolated (Abraham et al., 2021).

Vedas: the oldest and sacred religious text that provides knowledge and wisdom to all Hindus (Laher & Padayachee, 2014).

2.1.2 Medical Terms

Dementia: a neurodegenerative disease which is characterised by the decline of an individual's cognitive functioning, progressively, which leads to physical impairment and mental distress (Chang et al., & Patel, 2017).

Healthcare Workers: Individuals' who form part of a multidisciplinary team, who work and provide a service to those who are sick. e.g. for the context of this study, the multidisciplinary team mentioned include both Psychologists and Psychiatrists (Joseph & Joseph, 2016).

Neurodegenerative Disease: primarily characterised by loss in the function of an individual's neurons in their brain which later die (Chaulagin et al., 2022).

2.2 Etymology of Dementia

In a study concerning the 'History of Alzheimer's Disease' conducted by researchers Kim et al. (2016), the word 'Dementia' is of Latin origin. The prefix 'de', refers to the concept of 'loss' and the root of the word 'men' refers to an individual's mind. The suffix of the word 'ia' is indicative of a way of being. As a collective, the word Dementia gained the description, "a state out of mind" (Kim et al., 2016, p.1).

In conjunction, Kaplan's (1996) formulation of the word Dementia differs from that of Kim et al. (2016) because the prefix '*de*', means 'from', and '*mentis*', which means mind, both describe the disease as being "from the mind".

By comparing the two different ways of the word 'Dementia' being broken down into its origin – the basis of the disorder remains the same. The mind is the main aspect of the individual that is affected (Kim et al., 2016).

2.3 Definition of Dementia

The Archbishop of Seville, during 600 A.D, was the first person who recorded the word 'Dementia' in his book *Etymologies* (Kim et al., 2016).

The academic characterisation of Dementia is that it is a neurodegenerative disease which is characterised by the decline of an individual's cognitive functioning, progressively, which leads to physical impairment and mental distress (Chang et al., 2017). According to Oh and Rabins (2019) Dementia is merely a syndrome, wherein, Alzheimer's Disease is the most common form.

The manner within which Dementia presents itself differs. Despite the different clinical presentations, most individuals living with Dementia may experience deficits in their cognitive functioning (Chang et al., 2017). These cognitive deficits include memory loss, language, and communication delays as well as other functional impairments: agnosia (refers to the inability of recognising different objects) the inability to function daily based on prior memory of fulfilling tasks (e.g., remembers how to go to the toilet, brush their teeth, and drive a vehicle) whilst also experiencing a decline in how an individual reasons and plans (Chang et al., 2017). In addition, an individual living with Dementia is also subject to displaying changes in their personality (Baldwin et al., 2005).

Another important characterisation of Dementia is an individual's decline in social abilities. Most individuals who are diagnosed with Dementia often find it difficult to maintain relationships with others due to their lack of awareness with regards to the present moment (Clare et al., 2020). Additionally, their ability to participate in a community is minimal due to their lack of confidence as well as underlying fears and worries which lead to restrictive social opportunities (Clare et al., 2020).

In order to diagnose Dementia, it is important to note that there are other disorders and conditions that present with similar symptoms to that of Dementia. Kaplan and Sadock (2015) indicate that substance abuse due to medication is one of the conditions that has symptoms which imitate Dementia. In addition, major head injuries, Human Immunodeficiency Virus (HIV)- related Dementia and depression also present with similar symptoms to Dementia (Kaplan & Sadock, 2015, p. 694). It is imperative to note, that while HIV is not a form of Dementia, HIV- related Dementia or HIV associated Neurocognitive Disorder (HAND) "is a neurological condition that affects some individuals living with HIV/AIDS" (Hussain et al., 2024, p.2). Despite this, HIV- related Dementia does have symptoms that overlap with Dementia of Alzheimer's type, these include: memory impairment, slowed thinking, reduced apathy, slow motor coordination as well as a decline in daily functioning (Hussain et al., 20204). Noting the difference between the two is imperative, as it can affect the treatment and misdiagnosis of HIV- related Dementia and Dementia of Alzheimer's type (Hussain et al., 2024). Delirium which is often considered to be the same as Dementia, differs due to the fact that it refers to "short term confusion" and marked changes in the way an individual perceives, responds to and retrieves information (Kaplan & Sadock, 2015, p.694).

The difference between Delirium and Dementia is that Dementia occurs over a period of time with marked deficits in cognitive impairment and an individual's memory, whereas, Delirium has an abrupt onset and affects an individual's attention and their awareness (Fang & Gogia, 2023).

Therefore, an accurate diagnosis of Dementia requires evidence of short-term and long-term memory impairment. The impairment in short term-memory, according to Thompson (2006) refers to an individual's inability to recall at least three different objects within a five-minute time frame. Whereas, impairment in long-term memory refers to the inability to remember information that is personal and requires the individual to recall information from their past (Thompson, 2006).

2.4 Types of Dementia

There are four major types of Dementia namely, Alzheimer's Dementia (AD), Cerebrovascular Dementia (VaD), Frontotemporal Dementia (FTD), and Dementia with Lewy Bodies (DLB) (Chen et al., 2006). The Alzheimer's Association (2023) have differentiated the four major types of Dementia as follows:

2.4.1 Cerebrovascular Dementia

Individuals who are diagnosed with Cerebrovascular Dementia experience deficits in their planning, judgement, and reasoning abilities as well as experience difficulties with their memory (Bhaskar et al., 2016). Cerebrovascular Dementia is caused by damaged blood vessels in the brain. Due to the damaged blood vessels, an individual's brain does not receive enough blood, nutrients, and oxygen (Bhaskar et al., 2016).

Other factors such as diabetes, high blood pressure, increased levels of cholesterol, and heart diseases as well as a stroke, are considered risk factors for developing Cerebrovascular Dementia (Knopman, 2003).

2.4.2 Frontotemporal Dementia

Unlike Cerebrovascular Dementia that affects the blood flow and oxygen to the brain, Frontotemporal Dementia occurs as a result of damaged neurons in the temporal and frontal lobe regions of the brain. Individuals who are diagnosed with Frontotemporal Dementia experience difficulty performing physical tasks such as walking; they exhibit uncharacteristic behaviours; they have extreme difficulty communicating with others, and experience emotional turbulence (Rohrer et al., 2013). This form of Dementia is considerably rare and¹occurs amongst individuals who are between the ages of 45 – 64 years old (Alzheimer’s Association, 2023).

2.4.3 Dementia with Lewy Bodies

Lewy Body Dementia is characterised by the abnormal deposits of a protein, known as alpha-synuclein, found in the brain that develop in the cortical region of the brain and are known as “Lewy Bodies” which affect the way that the chemicals in an individual’s brain changes (Aarsland et al., 2015). As a result of these chemical changes, processes such as reasoning, abstract thinking, physical movement, and behaviour are affected. This type of Dementia is regarded as the second most common cause of the condition (Aarsland et al., 2015; Alzheimer’s Association, 2023). This is largely because its symptoms such as changes in cognition, attention, and alertness closely mirror the symptoms of Alzheimer’s disease, which is considered the most common form of Dementia (Alzheimer’s Association, 2023).

¹ The Alzheimer’s Association is a non-profit foundation that operates globally and was established and aimed to provide support to families and, their caregivers. The foundation is also involved in promoting awareness around Alzheimer’s as well as conducting research on the disorder alongside treatment advancements (Alzheimer’s South Africa, n.d.).

2.4.5 Dementia of Alzheimer's Type

For the purpose of this research study, Dementia of Alzheimer's type is the core focus of the research that is conducted. Due to the fact that, Dementia of Alzheimer's type is the most common form of Dementia amongst the elderly (Alzheimer's Association, 2023). The Alzheimer's Association (2023) agrees with Thompson (2006) that Dementia of Alzheimer's type makes up at least 50% of the Dementia diagnoses.

The degenerative neurocognitive disorder was named after a German Psychiatrist, Alois Alzheimer who worked with a patient, Auguste Deter, during his psychiatric internship in Frankfurt, Germany (Kim et al., 2016). In the case of Auguste Deter, Alzheimer was joined by Franz Nissl who was a doctor and neuropathologist in order to further study the symptoms presented by Auguste Deter. It was during this time, that Swiss Psychiatrist Emil Kraepelin, joined the research team in order to assist in the research process of Auguste Deter's case (Kim et al., 2016). Auguste Deter is described as a 51-year-old German female, who started displaying the symptoms of memory loss, delusions and cognitive decline (Kim et al., 2016). Initially, Auguste Deter' was diagnosed with 'Presenile Dementia' due to her age.

Alzheimer contracted with her husband Karl Deter, that Auguste's brain be donated to research upon her death (Kim et al., 2016). Karl had agreed and at the age of 55-years-old, Auguste had succumbed to her death after contracting Pneumonia in 1906 (Kim et al., 2016).

The symptoms that Auguste Deter displayed before her passing were significant as they are consistent with the symptoms of Alzheimer's disease today (Kim et al., 2016). Her symptoms were: "progressive cognitive disorder, local neurological symptom, hallucination, delusion, and psychological social disability" (Kim et al., 2016, p.118). Alzheimer's as the term given to a progressive cognitive decline disorder was given by Kraepelin. He believed that the discovery of Auguste Deter was significant in Psychiatry and Alois Alzheimer, who began researching her case, deserved the acknowledgement. In 1910, Kraepelin revised a

psychiatric textbook to classify the degenerative neurocognitive disorder (Kim et al., 2016).

As a result, the word ‘Alzheimer’s’ has been used for more than a century, since this textbook revision in 1910 (Kim et al., 2016).

Alzheimer’s disease is characterised by “senile plaques, neuritic tangles, and progressive loss of neurons” (Daiello et al., 2008, p. 16). Whereas, Dementia that results from having

Alzheimer’s disease is characterised by a decline in how an individual cognitively functions in relation to their short-term memory, and their ability to speak utilising the correct language (Daiello et al., 2008). Individuals who exhibit symptoms of Alzheimer’s are most likely unable to recall information such as their relatives’ contact numbers or the sequence of recent events in their life (cited by Biernacki, 2001 in Valoo, 2016).

Alzheimer’s disease occurs first before it later progresses to Dementia. Hence, clinicians are expected to diagnose Alzheimer’s primarily before a diagnosis for Dementia can be considered (Bredenoord et al., 2022). Alzheimer’s disease is considered as the main cause of Dementia, which is now characterised as a “lethal and expensive” burden within today’s world (Okhravi et al., 2022).

In a study conducted by Hugo and Ganjuli (2014) clinicians experience challenges when diagnosing patients who display symptoms of Dementia. Identifying the specific changes in a patient’s cognition is considered as the most challenging aspect because the element of a slow cognition, is normal as individuals start to age (Hugo & Ganguli, 2014). The cognitive changes that families usually report are often described as the loss of memory, however, clinicians understand that the identification of memory loss is also coherent with cognitive decline and various cognitive abilities (Hugo & Ganjuli, 2014).

In order for an accurate diagnosis to be made, the clinician is required to observe whether the changes in the patient’s cognition are clinically significant. In other words, there is marked

impairment in the patient's social as well as their occupational functioning (Hugo & Ganjuli, 2014).

Determining the aetiology of the cognitive impairment is considered as another challenge for clinicians when diagnosing (Hugo & Ganjuli, 2014). Hence, when clinicians are in the process of diagnosing the syndromes of Dementia, it is important to consider the patient's history, ensuring an examination is performed and, utilising the DSM-5-TR, as the standard measure of criteria in order to deduce an accurate diagnosis for the disorder (Hugo & Ganjuli, 2014).

2.5 DSM-5-TR Criteria for Dementia of Alzheimer's Type

Dementia is no longer subsumed as "Dementia" in the DSM-5-TR. It is now considered as "*major neurocognitive disorder*". According to the DSM-5-TR, the criteria that needs to be met for Dementia of Alzheimer's Type is as follows:

Major or Mild Neurocognitive Disorder Due to Alzheimer's Disease

Diagnostic Criteria according to the DSM-5 TR (APA, 2022, p. 690-691).

"A. The criteria are met for major or mild neurocognitive disorder.

B. There is insidious onset and gradual progression of impairment in one or more cognitive domains (for major neurocognitive disorder, at least two domains must be impaired).

C. Criteria are met for either probable or possible Alzheimer's disease as follows:

For major neurocognitive disorder:

Probable Alzheimer's disease is diagnosed if either of the following is present;

otherwise, **possible Alzheimer's disease** should be diagnosed (APA, 2022, p. 690).

1. Evidence of a causative Alzheimer's disease genetic mutation from family history or genetic testing.

2. **All three** of the following are present (APA, 2022, p. 690):

a. Clear evidence of decline in memory and learning and at least one other

cognitive domain (based on detailed history or serial neuropsychological testing).

b. Steadily progressive, gradual decline in cognition, without extended plateaus.

c. No evidence of mixed aetiology (i.e., absence of other neurodegenerative

or cerebrovascular disease, or another neurological, mental, or systemic

disease or condition likely contributing to cognitive decline) (APA, 2022, p. 690)".

For mild neurocognitive disorder:

- **Probable Alzheimer's disease** is diagnosed if there is evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history (APA, 2022, p.690).

- **Possible Alzheimer's disease** is diagnosed if there is no evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history, and all three of the following are present (APA, 2022, p. 690):

1. Clear evidence of decline in memory and learning.

2. Steadily progressive, gradual decline in cognition, without extended plateaus.

3. No evidence of mixed aetiology (i.e., absence of other neurodegenerative or

cerebrovascular disease, or another neurological or systemic disease or

condition likely contributing to cognitive decline).

D. The disturbance is not better explained by cerebrovascular disease, another neurodegenerative disease, the effects of a substance, or another mental, neurological, or systemic disorder (APA, 2022, p. 690).

The duration of the illness is said to have a minimal duration for at least six months up to approximately 20 years (Potocnik, 2013).

2.6 Stages of Dementia of Alzheimer's Type

Due to the fact that there are different types of Dementia, each type remains progressive. Progressive refers to the fact that over a period of time, symptoms will appear differently (Arvanitakis et al., 2019). At first, the symptoms of Dementia may be presented mildly, whereas, after several years the symptoms will be significantly worse. As a result of this progression, supervision as well as extra care and support is required from caregivers depending on the level of severity that the symptoms are presented (Arvanitakis et al., 2019).

There are three main stages of Dementia which are classified within the Diagnostic Statistical Manual of Mental Disorders, Fifth Edition - Text Revision (DSM-5-TR). These stages are considered to be indicative of the severity of Dementia. The stages are known as mild, moderate, and severe. These stages are indicative of the severity of the symptoms that affect an individual (DSM-5-TR, 2022).

According to the DSM-5-TR (2022) the stages of Dementia are described as follows:

First Stage: individual experiences mild symptoms of Dementia. This is exhibited by the inability of an individual being able to conduct their daily activities. Minimal support is required.

Second Stage: is characterised by symptoms that are moderately severe. Individuals within this stage experience difficulties with activities that are basic during their daily routines such as dressing themselves. Support is required but not fully.

Third Stage: is described as stage whereby the symptoms are severe to such an extent that an individual is unable to carry out any of their daily functions such as remembering to switch off the stove. As a result, the individual within this stage is fully dependent on their caregiver.

In addition to the levels of severity categorised in the DSM-5-TR (2022) Arvanitakis et al. (2019) tabulated the different symptom manifestations according to earlier and later stages of Dementia – across different domains.

Within the cognitive domain, short-term memory deficits such as forgetting important dates for appointments as well as difficulty finding words to articulate/communicate with are present during the earlier stages. In conjunction, during the later stage – memory loss with regards to processing and retaining information is poor (Arvanitakis et al., 2019). In addition, “Global Aphasia” which refers to a complete loss of vocabulary due to marked difficulties experienced when communicating with others is exhibited (Arvanitakis et al., 2019).

Psychological symptoms such as apathy which refers to the inability to act on an individual’s thoughts or actions as well as depressive symptoms such as feeling worthless are present during the early stage. Symptoms present during the later stage, within this domain, are manifested as anosognosia and delusions (Acharya & Sanchez-Manso, 2023). Anosognosia refers to the lack of insight that an individual holds with regards to salient aspects of their life such as having a disorder or a disability (Acharya et al., 2023). Whereas, delusions refer to fixed false beliefs that an individual maintains which are internally driven, but have no validity in their external environment (Chaudhury & Kiran, 2009).

These psychological changes can be better understood through Reisberg et al.’s (2002) concept of retrogenesis. Retrogenesis is defined as “the process by which degenerative mechanisms reverse the order of acquisition in normal development” (Reisberg et al., 2002, p. 202). According to Reisberg et al. (2002) it is a common process that is seen in individuals

diagnosed with Dementia, Alzheimer's, and other related neurocognitive disorders. This is because the regressive state that is noted amongst individuals diagnosed with Dementia of Alzheimer's type start to resemble behaviours that appear 'child like' (Reisberg et al., 2002).

Linking this to the concept of retrogenesis, the cognitive deterioration that occurs amongst Dementia diagnosed individuals, occurs in a reverse order that is not normal to the developmental process stages of a child (Reisberg et al., 2002; Xie et al., 2023). In other words, abilities one acquires later on in life are reported to be lost first, whereas the more foundational abilities remain preserved for a longer period of time (Reisberg et al., 2002).

Early symptoms such as depressive features and loss of apathy, typically suggest difficulties in an individual's complex thinking abilities as well as how they process their emotions.

Whereas, symptoms that present at a later stage, such as delusions or anosognosia are indicative of a more severe cognitive decline process (Acharya & Sanchez-Manso, 2023).

Aligning the above with Jean Piaget's theory of cognitive development, which is considered a measure of age-related development, and is described as "the sequence of biological, cognitive, and socio-emotional changes that humans undergo as they grow older" (Blake & Pope, 2008, p. 59). The theory further suggests that an individual's cognitive abilities develop from a simple to a more complex stage of thinking processes.

While retrogenesis is not explicitly derived from Piaget's theory, there is an assumption that cognition is sequential and structured. In contrast to one another, Piaget's theory of cognitive development focuses on how cognition is developed from one's childhood years. Whereas, Reisberg et al.'s (2002) concept of retrogenesis, focuses on how cognition is lost from one's older years in a reverse order (Reisberg et al., 2002).

This is seen in behaviours such as: difficulties with communication, a decline in one's basic self-care, a decline in one's ability to remember, and a strong attachment to caregivers.

Behaviours that Piaget identified as stages of earlier childhood development (Blake & Pope, 2008). Piaget's theory of cognitive development can be used to better understand the concept of retrogenesis, not in its literal sense but rather as looking at previously learnt cognitive and functional abilities lost – as a structured and sequenced process (Xie et al., 2023). Thus, Piaget's cognitive theory of development can help individuals such as Psychologists or Psychiatrists, identify patterns of cognitive decline and in turn take note of the demands that caregivers are placed under, as the neurocognitive disorder progresses.

2.7 Prevalence, Incidence, and Age of Dementia of Alzheimer's Type

The prevalence of a disorder/illness refers to the occurrence of a condition within a specific population (Reeler, 1986). Kim et al. (2016) suggest that due to the rapid aging of our society, there is a noticeable increase in the number of individuals who suffer from Dementia. Similarly, Daiello et al. (2008), stipulate that the prevalence of Dementia of Alzheimer's type is expected to increase due to a population's age increasing. This signifies that the prevalence of Dementia of Alzheimer's type and age exist mutually. The trend of this increase, is evidenced by indicating that almost five people per every hour, appear to develop or experience the symptoms of Dementia (Kim et al., 2016). However, Dr. Heather Rauch, a Clinical Social Worker, states that “every three seconds someone in the world develops Dementia” (Alzheimer's Association South Africa, 2021, para. 2).

Due to the high risk that is posed with Dementia of Alzheimer's type patients, the burden of expense has a direct impact on a country's economy. Kim et al. (2016) suggest that the only way to reduce this financial burden is to enforce early diagnosis through the implementation of mandatory check-ups as well as implementing interventions that are patient specific. This allows for a more personal approach to treating the disorder as symptoms present vastly different from patient to patient. In addition, not only is an early diagnosis effective for being

able to treat the disorder appropriately but it also improves the quality of life for the patient who has been diagnosed (Kim et al., 2016).

Furthermore, early diagnosis is also a futuristic predictor of delaying the age of onset of the disorder which directly influences the prevalence of Dementia of Alzheimer's type by a reduction of at least 20% (Kim et al., 2016).

From a South African perspective, a cross-sectional study conducted by Combrinck et al. (2017) reveals that the prevalence of Dementia within Bloemfontein, in the Free State province amongst the elderly black population is 6%. This study was conducted with a relatively small sample of only 200 participants. Similarly to Combrinck et al. (2017), Albanese et al. (2023) examined the incidence of dementia in low- and middle-income countries and reported that the rate in South Africa is 12.5%. When these figures are compared, it suggests that the rate of dementia in South Africa has risen from 6% in 2017 to 12.5% in 2023 (Albanese et al., 2023).

Furthermore, research on the onset age of Dementia concurs across multiple studies that Dementia is a disease commonly exhibited amongst the elderly population. Craig et al. (2010) stipulate that the factor of age, is a significant risk factor for the onset of Dementia of Alzheimer's type. However, LoGiudice and Watson (2014) posit a different perspective, suggesting that despite age being a risk factor for Dementia, having Dementia is not a normal part of how an individual ages. The worldwide prevalence for individuals over the age of 60 years old, ranged from 5%-7% in 2014. In the year 2019, the prevalence rate of Dementia worldwide increased to 10.8% (Nichols, 2022).

It is evident amongst various research studies that as an individual ages, their risk for Dementia of Alzheimer's type increases. In addition, Gao and Ling (2021) suggests that while the risk factor for Dementia is increasing age, other factors such as the incidental and

prevalence rates of the disorder also increase. As a result, the burden of Dementia of Alzheimer's type amongst low- and middle-income countries is high. Feng et al. (2022) cite the Global Burden of Disease 2016 Collaborators (2019) by emphasising that the burden of Dementia posits an increasing weight on the public health field, which leads to issues of economic crisis as well as the implications of the disease on both the society as well as the patient's family.

For individuals who are 60 years old, the reported prevalence rate is 1%. In comparison, individuals who are 85 and older, are reported to have a prevalence rate of 30-40% which doubles every 7th year within countries that are still developing like South Africa (Potocnik, 2013).

Potocnik (2013) postulates that almost two-thirds of individuals who are diagnosed with Dementia, reside within developing countries such as United States of America and the United Kingdom. The prevalence for Dementia is concerning because it reveals that the incidental rates are said to double, every twenty or so years (Potocnik, 2013).

In developing countries, like South Africa, the prevalence of Dementia is reported to be 250 000 people who suffer from the neurocognitive disorder, whilst 35 000 suffer from Alzheimer's Disease (Potocnik, 2013).

It is essential for healthcare workers and researchers to emphasise monitoring the risk factors of Dementia as a means of preventing Dementia, globally (Feng et al., 2022). The Global Burden of Disease, Injury and Risk Factors Study (Global Burden of Disease) conducted within 2019 utilised literature, databases that are available to the public and individual's medical records to conduct a systematic analysis of the age, incidence, prevalence and death rates of Dementia diagnosed patients (Feng et al., 2022). Furthermore, daily adjusted life years (DALYs) were also considerable to observe. DALYs refer to the predicted number of

years, which are healthy, that an individual has left to live after having been diagnosed Dementia until they succumb to death. DALYs are considered as indicators of the burden of Dementia, which are used widely by healthcare workers and health researchers (World Health Organisation, 2006).

In light of the above, effective treatment as well as preventative measures need to be put in place in order to reduce the burden of Dementia of Alzheimer's type on a country, society, or families.

2.8 Dementia and Other Mental Health Diagnoses

Research conducted by Caspi et al. (2022) reveal that a relationship between Dementia and other mental health disorders exists. Defining a mental disorder is a difficult task because there are various different definitions of what a mental disorder is and how it is defined. The DSM-5-TR defines it as “a syndrome characterized by clinically significant disturbance” (p.14) that leads to impairment in an individual's daily functioning due to the dysregulation of processes that occur in emotional regulation, developmental processes and psychological processes (Kendler et al., 2021).

India, being one of the second largest populous countries, makes up 18% of the global population. India's large population contributes significantly to the burden of mental health disorders, globally (Ahmed et al., 2022)

Studies reveal that mental health disorders are a modifiable category of risk factors that remains unnoticed, when considering the various risk factors for Dementia (Chit et al., 2020). In a longitudinal study regarding Dementia patients who require long-term care, researchers Chit et al. (2020) within Rhode Island, USA published data regarding the association between mental health disorders and Dementia. clinical and diagnostic data from existing medical records, including dementia status and co-occurring psychiatric disorder diagnoses, to

examine the association between dementia and mental health conditions. The data that was extracted, was clinical and diagnostic data from existing medical records, highlighting the patients Dementia status as well as any co-occurring psychiatric disorder diagnoses, to examine the association between mental health conditions and neurocognitive disorders like Dementia (Chit et al., 2020). The data reveals that a significant percentage (65.1%) of the 200 candidates reported to have suffered from a psychiatric condition at least once before (Chit et al., 2020). Whilst 36.5% of participants revealed that they suffer with Anxiety and only 28.6% reported a diagnosis for Depression. In addition, 14.9% reported to have been diagnosed with insomnia (Chit et al., 2020). Based on these statistics, it is evident that a strong association between an existing mental health disorder and Dementia needs to exist. Furthermore, Chit et al. (2020) suggested that the data obtained from the study revealed a significant need for future researchers to conduct research of the relationship between Dementia and mental health disorders. As a result of understanding Dementia in relation to a mental health disorder also increases a patient's quality of life (Chit et al., 2020). Another advantage is that it would reduce the confusion that nursing staff within the study reported about, regarding their concerns about not being able to identify underlying mental health disorder symptoms due to the similarities of symptoms (Chit et al., 2020)

2.9 Hinduism, Family Dynamics, and Dementia

2.9.1 Origins of Hinduism

India developed in 3500 B.C. along two rivers, the Indus River and the Sarasvati River (see figure 2.1). These two rivers are collectively referred to as the “Indus-Sarasvati” people or the “Harappan” culture (Bajpai, 2011). Figure 2.1 below illustrates the geographical origins mentioned above of early Indian civilisation (Bajpai, 2011).

Figure 2. 1 A map of India



The Indus-Sarasvati people followed religious practices that were observed and compared to what is now known as Hinduism due to the various similarities present. This observation was made when a stone seal, which was discovered in the Indus-Sarasvati cities, revealed proof of various deities, different symbols as well as auspicious ceremonies that were held (Bajpai, 2011). Evidence of the Indus-Sarasvati civilisation following a religion similar to that of Hinduism, was seen on a flat stone seal whereby a meditating figure was depicted. This figure resembles what devotees know as Lord Shiva. Figurines and statues, made out of clay, crafted in a meditational position with the figure's hands clasped together are representative of acknowledging others, by means of the traditional Hindu greeting "Namaste" which directly translates to 'hello' (Bajpai, 2011).

The Sarasvati River later dried up, which forced those living near the river to move to other parts of India (Figure 2.1). This led to a challenge in maintaining the Indus-Sarasvati culture as the people who followed it were separated. As a result, the Indus-Sarasvati culture declined (Bajpai, 2011).

Those who migrated to other parts of India, settled in the northern and central parts of India, whereas some settled alongside the Ganges River. Existing tribes in these areas, were now sought after by the previous Indus-Sarasvati people in 1000 B.C. (Bajpai, 2011).

Due to the migration, it was evident that depending on where individuals settled – the establishment of new cultures and languages emerged. One of these being, the ‘Tamil’ language which back then up until today is representative of Indians who live/lived in the Southern region of India (Bajpai, 2011).

It was only in the period 600 B.C., whereby, India had developed a unifying culture that was not exclusive to only one region of India. Citizens who resided in the Northern, Eastern, Southern and Western parts of India were all practicing a similar culture (Bajpai, 2011). As a result of this unification of a culture, the philosophical ideas and practices that are pivotal to Hinduism, had emerged.

2.9.2 How Hinduism is practiced

Hinduism is a widely practiced religion across India. It consists of a wide array of different ways of practicing the religion as well as how it is observed (Oman et al., 2022).

The core of Hinduism is grounded in religious books and scriptures which exude inspiration to those who are not practicing the religion due to its peaceful, mindful, and holistic view of life.

It is considered to be the third largest religion globally because it is practiced in a predominantly large country such as India (Oman & Paranjpe, 2020). There is an estimated amount of 966 million Hindu devotees across India, Nepal, and Bali (Kramer, 2021).

According to Rao (n.d.) the main tenet of Hinduism is that it provides individuals who practice the religion, an opportunity to adapt their minds as a means of establishing a relationship with the Divine (God) present in all of human life. Mysorekar (2006) suggests that Hinduism is not just a religion that ought to be followed, it is a way of life for its devotees from the time of their birth until their death.

There are many schools of religion within the tenet of Hinduism, which may or may not hold a central belief for some individuals whilst for others, the belief may not resonate, this is because there is more than one belief system within Hinduism (Whitman, 2007).

Hinduism is often described as the religion whereby “many gods are worshipped” (Laher & Padayachee, 2014). The gods and goddesses are known as deities and are often personified as individual gods, but are worshipped as one (Patel, 2005). Brahma, who is known as the supreme God because he is the creator of the universe is revealed in three different aspects, namely: Brahma (the creator); Vishnu (the preserver) and Shiva (the destroyer) (Dublin City University, n.d.).

There is ample room for devotees of the religion to worship prophets from all over the world. This is because it is not considered a missionary religion (Khumar, 1994). There are various ways within which, Hindus worship. According to the religion, devotees are meant to worship God according to their own faith or dharma (Khumar, 1994). Dharma, according to Hinduism, refers to the guidelines that are provided for an individual’s life in terms of how to act (Whitman, 2004).

The novelty of Hinduism and its practice relies on the ancient scriptures that were written and are now known as the Bhagwad Gita, the Vedas, and the Upanishads (Laher & Padayachee, 2014). Inculcated in these ancient scriptures that are used up until today, are the religious values and beliefs of Hindus which encapsulate part of their identity in the world as well as how they perceive things, globally (Khosla et al., 2020)

The Vedas is the largest source of knowledge in Hinduism because it is the oldest form of religious scripture, which up until today is widely utilised by those who observe the religion. The Vedas are commonly observed as the entirety of truth that is delivered from God amongst individuals who in English are known as ‘Saints’ and in Hindi known as ‘Rishis’ (Laher & Padayachee, 2014).

Hinduism, as a philosophy, is built on a belief system that is holistic rather than concentrated on certain elements that are singular. This, in essence, allows for a more holistic view of “the way of life” which is essentially the core of Hinduism as opposed to being just a religion (Mysorekar, 2006, Abstract). This ideal is substantiated by Juthani (2001) who posits that the well-being of an entire community is pivotal rather than the well-being of one individual in isolation.

Similarly, this ideal of mutual interdependence within Hinduism and Indian Psychology, is the study of African Psychology (Juthani, 2001). A balance between the immediate family, the external family, and the broader community are key determinants for the emergence of harmony within that specific community (Chekki, 1996).

2.9.3 Astrology, Karma, and Reincarnation

Another aspect of a belief system tied to Hinduism is grounded in Astrology.

Astrology plays a significant role in the Hindu religion as well as the Indian culture, due to spirituality as well as the ideal of experiencing a premonition (Martins, 2022). The Vedas utilised astrology to formulate the Hindu calendar, whereby, all sacred practices are marked, on a yearly basis (Martins, 2022). Non-adherence to following the sacred calendar is considered as being ‘bad luck’ because each religious occasion is set on a day that holds significance according to how the planets are aligned (Martins, 2022).

The notion of how the planets aligned, in Vedic Astrology, posits that an individual carries the sole responsibility for their destiny based on the decisions that they make. Swiss Psychiatrist Carl Jung, founder of Analytical Psychology is quoted as sharing the same belief “everything that we are not consciously in contact with, appears to us in our destiny” (Martins, 2022, p. 33).

Considering this, the belief of what happens to an individual is formulated according to the Vedic belief of Karma and choices. Other philosophical tenets of Hinduism are rooted in the concepts of reincarnation and karma.

The impact of karma as an ideology, is one that holds a heavy weight, specifically for the individual who is diagnosed with a specific disorder or disease (Martins, 2022). Shifting blame to past choices and behaviour becomes the main aspect of how a disorder or disease emerged within an individual. In other words, from an Eastern perspective an individual who suffers with a disorder is ideally ‘paying the price’ for their past life (Laher & Padayachee, 2014; Martins, 2022).

According to Khosla et al. (2020) the experience of suffering and illness is directly attributed to karma as a result of performing bad actions or having bad intentions towards others. Based on this, the process of Samsara which refers to the rebirthing process releases individuals from their moksha. As a result, individuals are motivated to lead a life that is moral and intentional towards others, in a good manner (Khosla et al., 2020).

2.9.4 Mental Health and Hinduism

From a Hindu perspective, mental health and related disorders are considered as elements of nature and religion. In comparison to the way that a disorder such as Dementia is conceptualised from a Western perspective, Hindus hold a strong belief that spiritual forces are influential upon the presence of a disorder (Mysorekar, 2006).

The manner within which mental health is understood in Hinduism, defines the individual as being part of “a whole in which the mental, physical and spiritual aspects of the self is not divided into separate categories” (as cited by Kakar (1982) in Khosla et al., 2020, p. 32). The dichotomous use of mental health in relation to illness is nothing but that of using language in a manner that may cause degradation upon an individual diagnosed with a mental health illness (Khosla et al., 2020). However, despite this, language informs a significant part of our understanding especially in terms of how we relate to things or people. Keeping this in mind, the use of the words “mental” and “illness” have contributed to the way within which healthcare professionals have been trained (Khosla et al., 2020).

The importance of understanding the dichotomous use of language within the context of this research study, is to highlight how in conjunction with health – illness exists on the opposite end of a continuum. As a result of this, “mental illness” holds a negative connotation as opposed to “mental health” which in turn influences how people perceive the two terms as well as how they relate to individuals diagnosed with a mental health illness (Khosla et al., 2020).

In comparison to the Western approaches of treating mental health disorders, Eastern approaches, specifically that within India, are aimed at treating the mind, body and soul of an individual as a whole as opposed to separate parts of one body (Khosla et al., 2020). In order to treat the mind, body, and soul – an individual is required to be in ‘Swastha’ which is a Sanskrit word that refers to “being in one’s natural state” as a means of being healthy without any health complications or abnormalities (Khosla et al., 2020). Furthermore, to be in ‘Swastha’ there is a requirement for an individual’s ‘mansa’ which is their level of awareness and their ‘ahara and vihara’ which is their mental status, to both be on the same level in order for an individual to be healthy (Khosla et al., 2020). In addition, the concept of being healthy within Hinduism is closely linked to a measure of an individual’s happiness and their well-being.

Spiritual illnesses are considered as the by-product of the evil eye, witchcraft, and being possessed (Khosla et al., 2020). When an individual is sick due to the presence of an evil spirit, they are considered to have a spell of bad luck cast upon them. The ailment of this bad luck is attributed to the individual’s karma that is passed on through a spiritual force (Khosla et al., 2020).

2.9.5 Indian Psychology

The origin of Indian Psychology was established on the basis of Hindu thoughts as well as the traditional practices. One of the significant reasons behind the emergence of Indian Psychology is the successful outcome of the treatments implemented (Oman et al., 2022). Due to the fact that unlike the traditional medical model which focuses on pathologising and treating a patient with medication, Indian Psychology focuses on an individual’s holistic well-being, their health, and their ability to function in their personal capacity (Fowler, 1997; Oman et al., 2022).

2.9.6 Cultural and Religious Conceptualisation of Dementia

Culture is defined as an accumulated experience that is taught to individuals from a young age, whereby, the focus is to preserve knowledge and traditions from generation to generation (Birukou et al., 2009). This is why conceptualising a specific mental health disorder or illness remains a difficult task, more so, for cultural communities. The ability to conceptualise a mental health illness or disorder is not universal because there are a significant number of different cultures, even within Hinduism, which understand and perceive a specific symptom differently (Laher & Padayachee, 2014). This is based on the ideal that culture is taught from one generation in order to be passed down to another. Due to this, the way that specific aspects of a culture are defined and/or shaped are based on the way a culture influences this process. As a result, the implementation of treatment may also be affected depending on the specific cultural traditions (Laher & Padayachee, 2014).

In light of this, conceptualising Dementia within the tenet of Hinduism as a religion, rather than just a philosophy, requires that Dementia be a separate entity or disorder that exists without considering the various Hindu beliefs regarding an individual's spiritual as well as physical health. Furthermore, Kazmin (2017) reports that the largest problem in India, regarding the idea of Dementia as a degenerative disorder, is that it is seen as part of an individual's ageing process. Due to this, the way that Dementia is understood and treated is an alarming factor for healthcare workers in this region (Kazmin, 2017).

In a study conducted amongst Indians residing in New Zealand, regarding families' experiences living with a Dementia relative, it was reported that the impact of a Dementia patient is not merely just financial, but rather emotional as well (Bala et al., 2022). The participants within this study were asked various questions, in order to establish their awareness of the degenerative disease. A few themes had emerged from Bala et al.'s study which is consistent with the themes in other studies. Participants were further asked to

describe how they perceive Dementia, after being given a precise definition by the interviewer of the disorder. The results revealed that defining the disorder was difficult (Bala et al., 2022). As a result of the language barrier, whereby, most participants claimed the difficulty of being unable to translate ‘Dementia’ from English to Hindi because there is no existing word for this disorder in the Hindi dialect (Bala et al., 2022). This reveals that the disorder is difficult to conceptualise, as it is difficult to translate as there is no direct translation available.

2.9.7 Diagnosed Patient Experiences

Multiple studies that are conducted in India, reveal that individuals living with Dementia are marginalised as a result of being neglected by their families. In turn, this neglect leads to societal prejudices which contribute to the challenges already experienced by those who are diagnosed with Dementia (Alladi et al., 2022). The difficulty that came with providing the relevant support for those that were diagnosed in the study conducted by Alladi et al. (2022) it is evident that socio-cultural beliefs of Hindu family members impacted the way that Dementia patients were treated. Despite the core tenet of Indian Psychology being about “community well-being” an interesting aspect from this core concept is clearly highlighted in the study conducted by Alladi et al. (2022). The utilisation of stigmatising language, alongside beliefs and behaviours led to treatment that was not sufficient. A lack of care also appeared to be a predominant theme within this study due to the poor understanding of Dementia that is exhibited (Alladi et al., 2022).

Cultural psychology demarcates the significance of how attitudes and experiences contribute towards the way a disease or disorder is understood in a manner that leads to marginalisation (Gan et al., 2023). This phenomenon is known as stigmatisation and occurs frequently amongst different cultures due to an underlying cognition that is grounded morally within a culture (Gan et al., 2023).

As a result of this, in conjunction with other research studies whose results concur with the ideal of stigmatisation against Dementia patients within the Hindu community and the Indian community in general, signifies the need for psychoeducation to be implemented.

2.10 Theoretical Framework: Bioecological Model

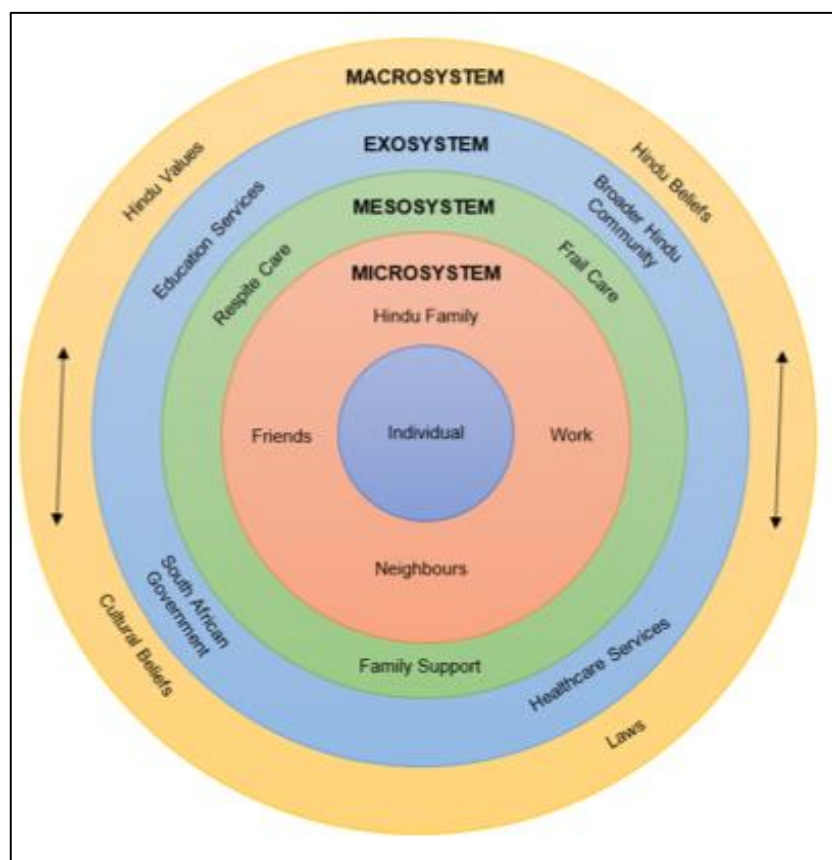
There are various tools which can be used in the discipline of Psychology, to study and understand human behaviour. In line with this research study, Urie Bronfenbrenner's Bioecological Model will be used not only to understand the significant impact of Dementia of Alzheimer's type on the individual within a system, but also to identify the factors that contribute to individual's experiences. And, how experiences involve stigmatisation, as well as lack of education surrounding the disorder and the marginalised treatment gap thereof. The theory was chosen to help frame the study, by means of exploring each level within a Hindu community and the impact of each on the diagnosed individual as well as their relatives who provide informal caregiving.

According to Predenville and Kinsella (2024) the Bioecological Model also provides an important interplay of dynamics, events, and behaviours that affect a person, time, and processes within a specific context. Crawford (2020) further elaborates on this in an article titled, *'Ecological Systems Theory: Exploring the Development of the Theoretical Framework as Conceived by Bronfenbrenner'*. Based on this article, the model aids as a lens, whereby, human development is viewed as an interconnected experience between an individual and their environment (Crawford, 2020). These interconnected experiences, however, do have an impact on the individual's psychological experiences as a result of the individual having experiences that shape their psyche.

Bronfenbrenner (1979) postulates that “human development is the product” of these interconnected experiences (p. 1). This comes as a result of the fact that as an individual what occurs within the individual’s system, is as a result of the different behaviours, interactions, beliefs, opinions, social views, governmental policies, law, and communal beliefs – that are upheld and/or displayed towards the individual. Bronfenbrenner (1979) postulated that these elements, albeit not all, do have a direct influence on an individual – which can either be negative or positive for that individual (Crawford, 2020).

Based on the theory, Bronfenbrenner (1979), outlined five systems seen in Figure 2.2 within an individual’s environment which he referenced as having a direct influence on human development and psychological growth (Adkins-Jackson et al., 2023).

Figure 2. 2 Urie Bronfenbrenner’s Ecological Model, adapted to the philosophy of Hinduism and Dementia for the purpose of this study (Guy-Evans, 2023).



The first system is the micro-system. At this level, the individual is considered to be interacting within the ‘smallest’ system. This level is considered to be the most significant level, as it is the direct system that the individual interacts with and has the most contact with (Berns, 2013). Within a micro-system level, the individual is also considered to experience a bi-directional influence, whereby, there is influence towards the individual as well as from the individual (Berk, 2000). Bronfenbrenner highlighted that at this level, the various interactions that individuals have with their complex environment shape their social and symbolic views of their environment as well as their relationships with others (Crawford, 2020). Furthermore, the individual’s personality as well as their temperament and personal belief systems have emerged at this level.

Considering an individual diagnosed with Dementia of Alzheimer’s type, at this level, will be influenced by their interaction with their families, their friends, as well as their informal caregiver (family relative). In tandem, families, friends, and the informal caregiver will also be influenced by the interaction they have with the individual who has been diagnosed with Dementia of Alzheimer’s type. These interactions are described to be significant as they have an impact on the other systems.

The second system is the meso-system which is considered to be the system, whereby, the connections within the individual’s structures in the microsystem are made. Bronfenbrenner defined it as “a system of microsystems” (Crawford, 2020, p. 2).

Linking to this research study, as an example, how respite care, frail care, and family support are implemented and provided within this system to the individual within the microsystem, which ultimately create the mesosystem. Both the microsystem and the mesosystem include the individual, whereas, the third and fourth system are systems that do not include the individual but instead have an impact on the individual (Crawford, 2020).

The third system, known as the exosystem consists of a larger system whereby the individual does not operate in (Berks, 2000). Healthcare services and education services, for example are likely to have an impact on the individual as these are services that an individual with Dementia of Alzheimer's type as well as their families are likely to sought after. Poor healthcare services or the lack of resources for education services has an impact on the microsystem as well as the mesosystem as both are likely to impede or decrease treatment as well as how the individual understands their diagnosis and how their family relatives are able to provide care and/or manage their diagnosis. Although this level, according to Crawford (2020) is perceived to be reciprocal, it does however depend on the context of the microsystem and what interactions or events are occurring.

In relation to the mesosystem, however, there is a reciprocal nature between individuals within this level as well due to the ideal that family relatives who provide informal caregiving may also be impacted by the lack of education services surrounding the diagnosis. Which further perpetuates the issue of misunderstanding a diagnosis or the experiences of stigma surrounding the disorder.

The fourth system known as the chronosystem, is a system that focuses on an abstract notion, known as time. At this level, time "is not only the aging and maturation of the person but also the time in which that person lives and develops" (Crawford, 2020, p. 2).

Considering Dementia, which was first discovered in 1906 by Alois Alzheimer, the disorder was not known otherwise. Significant to this, is that during this time, the University of Michigan had opened its first psychiatric hospital (Luchessi, 2021). This hospital was also known for providing cutting-edge research regarding how the brain functions as well as the genetic causality behind mental illnesses (Luchessi, 2021).

Interestingly, at this time, there were no known psychiatric hospitals in India. In the 1700's, as a result of the political unrest, psychiatric facilities were being established in Calcutta, Bombay, and Madras (Nizamie & Goyal, 2010). Despite the small fraction of the establishment of these facilities, it was during 1787 on the 3rd of April that a reference of the colonial influence on mental health was recorded in India (Nizamie & Goyal, 2010).

According to Ernst (1987) as cited by in (Nizamie & Goyal, 2010) the establishment of psychiatric hospitals was a “less conspicuous form of social control” (p. 8) due to the fact that these psychiatric hospitals were led by British Psychiatry. Additionally, access to these services was also only provided to the British soldiers at the time (Nizamie & Goyal, 2010). Highlighting that, at the time, the way mental health was understood – did not account for cultural ways of being, but instead was focused more on distinguishing between those who were considered as being ‘normal’ and those who were perceived at the time as a ‘lunatic’ (Nizamie & Goyal, 2010).

Based on the above, it is important to understand the history of psychiatry in India as a result of why there are misconceptions and stigmatisation of mental health illnesses. In addition to the above, Colonialism and Apartheid in South Africa did not provide adequate psychiatric care to South Africans of Indian origin (Kleintjies & Schneider, 2023).

2.11 Social Constructionism of Stigmatisation

Goffman (1968) as cited in Gan et al. (2023) differentiated the word ‘stigma’ as a form of labelling not only an individual but a group of individuals that share a common characteristic, attitudes, or status. These individuals are often misunderstood, perceived as different in a negative manner, and are excluded from society due to embarrassment, humiliation, and public discrimination (Gan et al., 2023).

Stigmatisation occurs on various levels for different reasons. The cultural aspect of stigmatisation is one of the most common forms of marginalisation as each culture holds specific beliefs and values that are inherent to generations past and present (Gan et al., 2023). These cultural beliefs and values are usually preserved by a culture and any other attitude, belief or value that deviates against the culture's norm – is excluded and perceived as a threat (Gan et al., 2023).

Prior research conducted by the World Health Organisation (WHO) surveyed thirty participants. A significant number of participants, twenty-five out of the thirty, reported to have experienced stigmatisation in relation to Dementia of any type (Gan et al., 2023). These participants' narratives revealed that the impact remained negative. Furthermore, the stigma also impacted families and caregivers which led to further marginalisation (Gan et al., 2023).

There are two social constructs behind the word 'stigma'. Firstly, public stigma which occurs on a societal level and secondly, self-stigma which occurs individually within a person (Corrigan & Watson, 2002).

Public stigma, from a systems theory perspective, refers to the negative beliefs, attitudes and behaviours that are held and exhibited towards individuals who share the commonality of a specific disorder/disease and other times, those who belong to a specific community (Corrigan & Watson, 2002).

A stigmatised population often includes those who are affected by a disorder, such as Dementia, or a disease (Corrigan & Watson, 2002). This population is feared, rejected, and often avoided to reduce the risk of being infected or harmed, this is known as associative stigma (Corrigan & Penn, 1999; as cited by Goffman, 1968 in Gan et al., 2023).

As a result of public stigma, a process of "othering" occurs, whereby, individuals who are not affected by a specific disorder or disease, feel responsible to protect themselves from 'those'

who are affected (Alikhani et al., 2020). According to Alikhani et al. (2020) the notion of creating a separation between those who are infected as ‘them’ and those who are not infected as ‘us’ is distinct. This form of separation utilising specific words creates a perceptual distance between the two, whereby, a label is attached to the ‘them’ (Alikhani et al., 2020). As a result of this, fear, anxiety, and worry are reduced because those who are labelled are potentially disarmed and are unable to participate with those who are not affected (Alikhani et al., 2020). The exacerbation of fear and anxiety surrounding those who are affected or infected, is a common societal response to predominant diseases and disorders (Alikhani et al., 2020).

Whereas, unlike public stigma, self-stigma refers to the way in which an individual is perceived by and treated according to societal perceptions and negative attitudes (Corrigan & Rao, 2012). This phenomenon occurs frequently amongst individuals who are infected or affected. Often, feelings of worthlessness and shame are experienced which later leads to the fear of seeking care or appropriate services by the individual who is marginalised (Corrigan & Rao, 2012).

2.11 Social Constructionist View of Dementia

The way that Dementia is socially constructed, refers to the way that people think about certain aspects of life based on learnt expectations and views, dates back to the history of Dementia (Bosco et al., 2019).

2.11.1 History of Dementia

Researchers Bosco et al. (2019) believe that the stigmatisation of a disorder or illness, exists due to how society has been constructed throughout history by means of adjusting and adhering to societal norms and standards of certain behaviours, attitudes, and beliefs. Historically, when Dementia first emerged as a disorder amongst the elder generation it was carefully observed by the ancient Egyptians in the period 2000 B.C (Bosco et al., 2019).

The world renowned mathematician, Pythagoras, divided the human life stages into six categories; infancy which included unborn babies and toddlers until the age of six, the adolescence stage which included children from the age of seven until the early adulthood age of twenty-one, the stage of adulthood was classified between the ages of twenty-two to forty-nine, those who were middle aged were categorised from the age of fifty to sixty-two, those between the ages of sixty-three to seventy-nine were considered ‘senescence’ and lastly, oldest age group was classified between the ages of eighty and older (Bosco et al., 2020; Kim et al., 2016).

The significance of these stages were clear indicators of where an individual is in terms of their functioning both mentally and physically (Kim et al., 2016). Individuals who were part of the senescence and old age stages were both known to exhibit an absent-minded state as well as display limited physical abilities (Kim et al., 2016). The expectancy of these stages was described to “degenerate in mind [to] a level of suckling baby and finally become stupid” (Kim et al., 2016, p116).

2.11.2 Emergence of Dementia as a Socially Constructed Disorder

From a systemic perspective, the DSM-5-TR (2022) is considered problematic. This is because it over-medicalises disorders instead of considering the disorder by observing the individual who presents with the problem, in relation to their system (Bowen, 1978). Factors such as a family’s belief system, their values, their religion as well as culture are crucial to understand in order to understand the way that a mental health disorder is perceived.

Based on the above philosophy of Hinduism, the symptoms presented in Dementia are symbolic of an individual’s past life actions. This is commonly referred to as ‘Karma’ (Laher & Padayachee, 2014). Karma is a concept that relates to an individual’s bad thoughts, their innate jealousy as well as thinking bad thoughts about others. As a result of this negative behaviour, the individual is reborn into another life carrying the consequences of their past

life with them (Laher & Padayachee, 2014). For example, an individual who has been diagnosed with a mental health disorder such as depression would be seen as experiencing their 'karma' for whatever bad behaviour was exhibited in their past life.

A sub-theme identified in the study conducted by Bala et al. (2022) revealed that "Karma" was considered as the contributing factor towards the aetiology of Dementia amongst the Indian community, specifically, those who follow Hinduism. In addition, the result from this study concurs with the study conducted by Laher and Padayachee (2014).

The common theme between the two studies reveals that participants narratives are not subjective, but rather consistent with that of cultural beliefs. The main belief being that the concept of one's destiny is determined by an individual's past actions (Bala et al., 2022). As a result, participants were able to accept that their relative receiving a diagnosis of Dementia is attributed to their past behaviour because it is part of their destiny. Furthermore, the notion of Karma as a means of explanation behind a diagnosis for Dementia, remains a common element amongst various studies conducted within predominantly Indian communities/areas (Bala et al., 2022).

Often the idea of any type of disorder that relates to an individual's mind, is stigmatised due to how society perceives and understands the disorder (Bala et al., 2022). A lack of education regarding the disorder, is seemingly one of the most significant contributing factors as to why stigmas are still existent within the 21st century (Bala et al., 2022).

Taking the above into consideration, Hindus perceive a mental illness and a spiritual illness as two separate conditions, despite the fact that a spiritual illness may lead to a mental illness. As a result of this, individuals who display symptoms of spiritual illnesses are misdiagnosed due to the overlapping symptoms to that of a mental illness disorder (Laher & Padayachee, 2014). The three most common forms of spiritual illnesses to exist within the branch of

Hinduism are: the belief in the evil eye, an individual being spiritually possessed and the existence of witchcraft due to specific behaviours that are considered uncharacteristic (Laher & Padayachee, 2014).

Whilst mental health illnesses and disorders appear different to other medical conditions in terms of their clinical presentation, a common thread that exists between the two within the philosophy of Hinduism is that being associated with either an individual who has a mental health illness or a disorder, would increase the other persons chances of experiencing their own mental health problems. This in turn, leads to the person who has a diagnosis to be marginalised from their community or family as a result of fear that is established (Laher & Padayachee, 2014).

2.12 Family and Caregiving

The notion of a family caregiver is a common aspect of today's society. Those who are responsible for their Dementia relative are commonly referred to as the "invisible second patient" (Brodaty, 2009, p.322).

The impact of a caregiver on a Dementia patient is just as crucial as the impact of a Dementia patient on a caregiver since they both interchangeably dictate both the patient's and the caregiver's quality of life (Brodaty, 2009). Depending on the severity of the patient's diagnosis, caregiving services are pivotal for Dementia patients (Brodaty, 2009). Informal caregivers are often employed to supervise a Dementia patient, on the basis that the patient stays at home (Kipfer & Pihet, 2018).

In India, the concept of a caregiver is almost non-existent. An individual that is diagnosed with Dementia, within a Hindu family, is usually taken care of by family members. This leads to the notion of the family member taking on the role and responsibility to act as an informal 'caregiver' for the diagnosed patient (Brodaty, 2009). Additionally, the idea of taking care of

a family member with Dementia leads to certain experiences which may either be pleasant or unpleasant. These experiences are often attributed to cultural expectations as well as cultural misinformation regarding how a disorder/disease develops (Brodaty, 2009).

In addition, a study conducted in China, also wherein collectivistic cultural values predominate, revealed a similar theme of care. Calia et al. (2019) reported that a predominant form of care for individual's diagnosed with Dementia, in China, are taken care of by their family members. Similarly, to the culture of Hinduism. However, the downfall of utilising informal family caregiving services results in a lack of knowledge and skills surrounding the neurodegenerative disorder, which directly impacts the individual who is diagnosed (Calia et al., 2019).

Depending on the cultural expectations, the experience is usually positive wherein the patient who is diagnosed does not present with severe symptoms and that the relationship between the family caregiver and the patient is not tainted by the patient presenting as being difficult (Brodaty, 2009). Contrastingly, a negative experience consists of the misinterpretations of the disorder that are characterised according to cultural beliefs. These cultural beliefs are on the opposite end of a continuum, in conjunction with the medical model that exists to explain the aetiology of Dementia (Brodaty, 2009).

The general effect of family members taking care of a Dementia patient is negative because of the increased rate of burdens that are placed onto the family caregiver. Burdens such as increased financial expenses, being isolated from social events and society as well as the burden of experiencing psychological and physical health difficulties (Brodaty, 2009).

Bala et al. (2022) reveal that almost 10% of the population living in Aotearoa/New Zealand are Indian. An estimate of 70 000 people living in New Zealand have Dementia. However, according to the study this figure is expected to double by the year 2040. The increase is

projected to be seen predominantly amongst the Indian population due to the rapid ageing demographic that exists (Bala et al., 2022).

The most prominent themes identified in the study regarding caregiving, revealed that majority of the caregivers living with a Dementia relative are prone to developing misconceptions as well as lack awareness regarding the neurodegenerative disorder (Bala et al., 2022). Caregivers who participated in the study, described the difficulty of living with a Dementia relative (Bala et al., 2022). The difficulties included misunderstanding the relative's diagnosis as well as the lack of information surrounding appropriate medicinal dosages and the inability to relate to the diagnosed patient (Bala et al., 2022). A significant contribution to the misunderstanding of Dementia reported stemmed from the lack of appropriate information. This was reported as the lack of proper communication from a medical practitioner regarding the disorder as well as the lack of follow-up appointments after a patient received a diagnosis (Bala et al., 2022).

The impact of Dementia on the caregiver's social life revealed that conflict was established between the caregiver and the patient. As a result of this, the caregiver would develop feelings of frustration and resentment as well as feel demotivated to continue fulfilling their role as a caregiver due to the lack of completing certain tasks or activities (Bala et al., 2022).

Additionally, the theme of satisfaction is a prominent feature of caregiving services. In the study, a prominent response amongst the caregivers revealed that majority were content with the support they received when looking after a Dementia patient (Bala et al., 2022). Support when looking after a Dementia patient is pivotal as it makes the process of care easier. However, this may change depending on the severity of the patient's diagnosis (Bala et al., 2022).

In contrast to the Hindu family caregiving experiences, there is a common thread regarding the overall experience of caregiving. In that, it was reported that most caregivers experience symptoms of stress and fatigue as well as become isolated from society (Siette et al., 2023).

The level of support amongst caregivers and a patient's family, is significant when observing how Dementia is understood. A lack of awareness usually leads to stigmatisation, whereas, 'awareness' is usually indicative of a successful treatment and support service for the patient (Siette et al., 2023). The existence of appropriate awareness is pivotal in reducing the stigma surrounding the neurodegenerative disorder.

2.13 Community Awareness

Discussions regarding the existence of community awareness of Dementia of Alzheimer's type, have dominated various research study over the years. The impact of awareness is marked as being relatively 'low'. This has critically influenced how the neurodegenerative disorder is treated (Brennan-Horley et al., 2019). Researchers have posited that the lack of understanding surrounding Dementia leads to the existence of fear, societal exclusion, and the emergence of stigma (Brennan-Horley et al., 2019).

Preceding research of how the Indian community understands Dementia is minimal.

However, a common finding between the study conducted by Bala et al. (2022) and Brijnath (2014) reveals that the stigma that exists around the disorder – contributes to the misunderstanding of the disorder. A prominent feature of how the Indian community understands the disorder is due to the disorder being 'part of the ageing process' as opposed to being understood as a biomedical disorder that affects an individual's neurodevelopmental processes (Bala et al., 2022; Brijnath, 2014).

To reduce the lack of awareness and stigma of Dementia within a community, psychoeducation and community-based workshops are considered appropriate strategies, that ought to be implemented (Brijnath, 2014). The increase of awareness surrounding Dementia would inevitably lead to a better response to the diagnosis as well as the treatment of the disorder.

Psychoeducation refers to the process of imparting knowledge regarding a specific disorder/disease with the diagnosed patient's relevant family members, caregivers, and the broader community within which the diagnosed patient exists (Brijnath, 2014). By means of imparting knowledge, a therapeutic environment that is founded on support is provided.

To promote the well-being of families, caregivers and the broader community who collectively support and take care of the diagnosed patient, it is pivotal to understand that being well informed on how to approach or handle certain situations with a Dementia of Alzheimer's type patient has a positive impact on the relationship between the various parties (Bala et al., 2022).

By implementing psychoeducational programs/interventions a sense of control is felt by the various family members and caregivers. It also increases how these individuals cope within their personal capacity after interacting with a Dementia of Alzheimer's type patient (Cachioni et al., 2011).

By taking the above into consideration, it is evident that there is minimal community awareness surrounding the knowledge and the awareness of the disorder (Mahlelehlele et al., 2023). Mahlelehlele et al. (2023) support this notion in their study conducted in Lesotho, reporting that "Ninety percent (90%) of females knew about dementia and perceived it as the disease that is inevitable in elderly as it is a part of the normal ageing process. Most males reported to not know about it and regarded it as witchcraft" (p. 3).

2.14 Treatment of Dementia of Alzheimer's type

From a Western perspective, there is no cure for any form Dementia. However, recent research conducted by Burns and Overshott (2005) is indicative that there are advancements in terms of how Dementia (of any type) is treated. These advancements are made within the medication that is prescribed to diagnosed patients. Cholinesterase inhibitors (ChEIs) are considered to be the most effective medication for patients who are diagnosed with Alzheimer's disease. However, they are regulated in the United Kingdom and largely inaccessible due to the fact that they are unaffordable for the average working-class individual (Burns & Overshott, 2005). Whilst various pharmacological treatments are common for the management or treatment of Dementia of Alzheimer's type, it is important to note that there are no guarantees for the medication to work amongst every patient who takes it nor for the disorder to be cured (Burns & Overshott, 2005).

Non-pharmacological treatments which do not encompass the use of medication are commonly sought after in India. Interestingly, the best medication for an illness or disease from a Hindu perspective is to implement traditional healing practices (Khosla et al., 2020). Implementing traditional healing is considered as a holistic approach because the physical and external factors that are the root of an illness is taken care of through means of a traditional healer and/or a priest which are commonly referred to as a Pundit or a Guru (Khosla et al., 2020).

The traditional healer is responsible for mediating with God or the gods in order to reduce the presence of Bhut (evil spirits) and to ensure that balance within an individual's life is restored (Khosla et al., 2020). Furthermore, a link between the traditional healer and the supernatural can also be implemented by means of the traditional healer referring to religious texts and scriptures as well as interpreting 'messages' that are passed on from ancestors (Khosla et al., 2020).

The traditional healer, also known as the divine healer, is also able to resort to traditional measures of prayer. This is observed by lighting a ‘Diya’ which is the lamp in order to perform an aarti (a prayer). The aarti is recited to the deities, asking for healing over the individual who is ill (Khosla et al., 2020).

Other forms of traditional Hindu healing methods include tying a black thread or placing a black dot (kajal) on the individual’s forehead or behind their ear to prevent the evil eye from being casted upon the individual by other people. This practice is often conducted by a family member, usually an elderly member of the family (Khosla et al., 2020).

Understanding the underlying spiritual nature of an illness, allows the traditional healer to successfully implement the corrective traditional practice, which later resorts in holistic healing for the patient (Khosla et al., 2020). Other forms of traditional healing include: Ayurveda, Siddha, Yoga, Unani, and Homeopathy (Khosla et al., 2020).

From a Western perspective, non-pharmacological treatments for individuals diagnosed with Dementia of Alzheimer’s type include respite care and frail care (Annemans et al., 2019).

Respite care refers to the “temporary relief” provided to the caregiver of a Dementia of Alzheimer’s patient, by means of providing a new environment for the caregiver to recuperate their energy whilst a temporary individual takes their place of formal caregiving for the patient (Annemans et al., 2019). The Alzheimer’s Association (n.d.) classifies the different forms of respite care as: respite care by other family members, respite care from friends, respite care at home and respite care in an adult care facility that can be long-term.

Dementia of Alzheimer’s type patients are often transported between a hospital and at times a nursing home or step-down clinic. This constant movement does have an impact on the patient’s well-being as they do not have a stable environment that allows them to feel safe or secure in (Annemans et al., 2016). As a result of this, respite care is also applicable to the

Dementia of Alzheimer's type patient. In addition, respite care provides patients with opportunities to be in a safe environment, whereby, other individuals with similar experiences are present (Alzheimer's Association, n.d.).

In conjunction, frail care is also a significant form of non-pharmacological treatment for Dementia of Alzheimer's type patients. Frail care refers to services of care that are provided to the elderly due to their inability to conduct their day-to-day activities independently because of auditory problems or cognitive deficits (Ek Dahl, 2012). The physiological changes in patients who have been diagnosed with Dementia of Alzheimer's type are more prone to be considered as "frail" depending on the level of severity of their diagnosis. According to Clegg et al. (2013), as cited in Nieuwenhuis (2020), Dementia in combination with frailty is considered a high-risk factor due to behavioural issues that are observed in the diagnosed patient, such as screaming, wandering, disorientation and repeatedly asking the same questions. These behavioural issues are often overwhelming for the patient's family, specifically, those family members who are the patient's main caregiver (Nieuwenhuis, 2020). Furthermore, additional support for the family caregivers is required as a means of decreasing the family caregivers' chances of experiencing stress, to the point, that may result in Depression (Nieuwenhuis, 2020).

In addition to the above, other non-pharmacological treatments that are aimed at supporting family members and the broader community, include the implementation of psychoeducation and community-awareness programmes (Siette et al., 2023). This is because a positive outcome is noted for both the family caregiving system and for the diagnosed patient. By implementation of either psychoeducation reduces the stigma as well as improves the support provided and the access of treatment – the outcome of these interventions is subjective. Prior research found that the existence of stigma within a community regarding a disorder, does

contribute to an individual's inability and/or their unwillingness to seek treatment (Siette et al., 2023).

Chapter 3: Research Methodology

3.1 Introduction

Research involves performing the task of acquiring information that is new and useful to answer questions based on a specific scientific phenomenon or social problem (Goundar, 2012). According to Goundar (2012) the word “research” when broken up into its prefix “re” meaning “again or anew” and “search” which refers to the process of observing or examining something very closely. When put together, a noun is formed, that describes research as “a careful, systematic, patient study and investigation in some field of knowledge, undertaken to establish facts or principles” (p. 2).

Research methodology, also known as the research process, refers to the process of logically and systematically carrying out certain tasks and taking various steps, to conduct and obtain information that is useful for the researcher. In this chapter, the methodology that was utilised will be further discussed. Drawing on the procedures that were undertaken in order to answer the research question. Due to the extensive steps that are taken, when conducting research, it remains a salient process to justify a specific research method, how participants were selected for the data collection process, and how the data will be analysed and utilised to extract various themes. The chapter will further discuss the researcher’s self-reflexivity and the importance thereof.

3.2 Research Problem

The research focused on the experiences of Hindu families who live with a family member, that has been diagnosed with Dementia of Alzheimer’s type. There are numerous studies which highlight the rapid increase of morbidity rates due to neurodegenerative disease, Dementia. As these rates increase, so does the need for interventions to be implemented (Jokogbola et al., 2018). There are no medicinal treatments for Dementia, which makes the implementation of primary interventions such as early diagnosis, cultural

awareness of how the disorder is perceived, and community awareness are significant factors to treating the disorder at a first-level basis (George et al., 2019). More so, with the rapid increase of morbidity rates, there is also an increase in families assuming the role of informal caregivers for their diagnosed family member (Iavarone et al., 2014).

In India, after a diagnosis of Dementia is made, elderly family members and females take on the responsibility of looking after the diagnosed patient. Factors such as religious beliefs, family expectations, and ethnic conceptualisations of the disorder affect the way that family's provide caregiving (Chryssanthopoulou & Milne, 2005). There are multiple studies conducted regarding Dementia of Alzheimer's type and the impact on caregivers, however, the existing body of literature on informal caregivers experiences does not address the impact of religion, such as Hinduism, on the caregivers experiences. Due to this gap in literature, there is a dire need for research addressing the religious parameters within caregiving to be conducted – specifically within a South African context.

3.3 Research Purpose

This research study was conducted to explore how Hindu families who provide informal caregiving, experience living with and taking care of an individual diagnosed with Dementia of Alzheimer's type. The study was also conducted to further understand how Hinduism has socially constructed the way that Dementia is perceived within a Hindu community as well as how religious practices influence the care of and treatment thereof regarding the neurodegenerative disorder.

In line with the research objectives, the research study explored the challenges that family members encounter, specifically with regards to seeking support from the Hindu community, as well as seeking corrective treatment measures for their diagnosed family member. Additionally, the study also aimed at identifying the psychological, physical, social, and

financial burden that impedes the caregiving process for both the caregiver and the diagnosed patient.

This body of research will contribute to the healthcare field by providing an alternate view of how religion impacts the way Dementia is understood, more so, how it may impact the treatment thereof. Furthermore, this research may also contribute to the way that the healthcare system and the policymakers involved in the healthcare field, establish a way forward to alleviate the gap of knowledge and to improve the cultural exposure of training healthcare workers within the various fields.

Mason (2002) suggests that the research question, formulates the backbone of a qualitative research study. It is described as the “phenomenon investigated” (Terre Blanche et al., 2006). The research question for this qualitative research study, refers to the main question that the study will explore. Due to the open-ended nature of a qualitative research question, participants are able to share their thoughts, feelings, and experiences regarding the investigated subject.

The main question that this study aimed to explore was concerned with the experiences of Hindu families who live and care for a Dementia of Alzheimer’s type patient. In addition, to explore the following questions which were secondary and aimed to further explore how Hindu families perceive and conceptualise Dementia, the contribution of Hinduism to the stigmatisation of Dementia, and how Hinduism affects the treatment and/or care of a relative diagnosed with Dementia.

3.4 Research Epistemology

Epistemology is considered a branch of knowledge within the field of philosophy (Cunningham & Fitzgerald, 1996). It is described as “the theory of knowledge” (Rescher, 2003, p. 14). Epistemology is further explained as a theory that invites an individual to “wonder”. In doing this, epistemology provides knowledge to individuals to further expand on and enhance an individual’s understanding of what is already known through new knowledge (Rescher, 2003, p. 16). It is a broader concept that is utilised to describe how individuals make sense of different phenomenon and problems that exist in the world.

The paradigm for this study adopted a *social constructionist approach*. The *ecological systems theory approach* theoretical framework was also adopted to explore the study.

Social constructionism refers to a perspective whereby Gergen (1985) as cited in Galbin (2014) hold the belief that social and interpersonal aspects of life, have a great influence on how human life is existent. The main element of social constructionism focuses on the subjective view of an individual and how this individual creates meaning of the world around them (Gergen, 1978). This is attributed to how an individual comments on a given society, how an individual negotiates their individualised meanings into society and how an individual constructs his/her understanding of the world around them (Gergen, 1978).

A relationship between Kenneth Gergen’s Social Constructionism theory and Urie Bronfenbrenner’s theory of Ecological systems exists. This is due to the fact that in social constructionism, particularly radical constructionism, “an individual functions in relation to its environment”. Similarly, in the theory of Ecological Systems an individual develops based on the interactions that they have with their surrounding environment and the influence of this environment on an individual (Berns, 2013).

The individualised perceptions and conceptualisation of Hindu families living with a Dementia of Alzheimer's type relative is therefore grounded in both of these theories due to the way that Dementia of Alzheimer's type is understood according to the broader Hindu community as well as how this perpetuates the stigma of Dementia of Alzheimer's type within the Hindu community. Therefore, the influence of the Hindu community and the Hindu religion (the macrosystem) can be perceived as the factor that influences how Hindu families respond to their relative, diagnosed with Dementia of Alzheimer's type (the microsystem).

In line with this, it is important to note that within these various ecological systems mentioned above, there is an interconnected pattern of relating that occurs between individuals. Murray Bowen's family systems theory, emphasises the interconnectedness of individuals that exist within a family unit (Bowen, 1978). This aligns with Urie Bronfenbrenner's ecological model that situates the family as a central unit that functions within a broader environmental context (Bronfenbrenner, 1979).

In the current study, Urie Bronfenbrenner's Ecological System's Theory model has been adapted to explore the philosophy of Hinduism and how this impacts the individual who is diagnosed with Dementia of Alzheimer's type based on the different levels, that are concerned with various factors, within the above model. Furthermore, the experiences of family members and healthcare workers will be explored according to the various levels and by analysing the interconnectedness of individuals within their various family units. This will be discussed in conjunction with the results from the research study once it has been conducted.

3.5 Qualitative Research Design

3.5.1 Research design

An exploratory and heuristic research design was chosen for this study to increase knowledge as well as gain new insight around a phenomenon (Hunter et al., 2019).

The reason the researcher employed a qualitative, exploratory design to explore how Hindu families experience a relative diagnosed with Dementia of Alzheimer's type. By focusing on how Dementia of Alzheimer's type is perceived and conceptualised, as well as treated within a Hindu household. It is significant to explore family members' experiences because they are subjective and often informed by social constructionist ways of viewing and perceiving a disorder.

3.5.2 Research approach

The research study adopted a qualitative approach. A qualitative research approach was chosen because it is "capable of producing very well-founded cross-contextual generalities" (Mason, 2002, p. 1). Busetto et al. (2020), further stipulate that qualitative research involves acquiring information within the study by providing an answer to the "why" questions.

Rahman (2017) further says that qualitative research focuses on an individual's experiences, their lives, their emotions, and their behaviour. It includes multiple realities that are derived at without any quantification (Rahman, 2017, p. 103). This is vital to qualitative research because an individual's feelings and thoughts, are aspects which are difficult to describe using numbers.

This type of inquiry involves conducting interviews, analysing texts, and making observations to inform themes towards answering the research question. Merriam and Tisdell (2016) stipulate that "humans are best suited for this task" (p. 2). In other words, the

researcher is the most important tool for collecting, observing, interviewing, and analysing a specific phenomenon.

Apart from qualitative research exploring subjective attitudes and experiences to understand a phenomenon, Braun and Clarke (2013) have highlighted that with qualitative research, words are used to collect data. Making the data collection process one that requires a deeper sense of rapport and empathy to be maintained between the researcher and the research participants.

A qualitative research approach is apt for this research study because it allowed the researcher to obtain thick, detailed descriptions of the participants' emotions, and their subjective experiences of being Hindu and how their religious beliefs and views impact their ability to care for and live with their relative, who has been diagnosed with Dementia of Alzheimer's type. Moreover, a dynamic and holistic emphasis was placed on family members' individual experiences to accurately capture each experience in its uniqueness and its entirety (Beck & Polit, 2004). This further allowing for a more nuanced understanding of how personal, relational, and contextual factors interact in shaping perceptions and responses within the family system.

In addition, a qualitative research approach allowed the researcher to explore how meaning is attributed within the Hindu culture and how those meanings are utilised to perceive and/or treat an individual who is diagnosed with Dementia of Alzheimer's type (Rahman, 2017).

Furthermore, the open-ended nature of a qualitative research approach ensured that participants' felt free to express what feels "consistent for them" (Rahman, 2017, p. 104).

Thus, an easier understanding of the investigated subject was provided.

In the present study, the researcher used semi-structured interviews as the main data collection method. The researcher used a predetermined set of both open and close ended questions which guided the interview conversation (Hesse-Biber & Levy, 2011). The research

interviews focused on asking questions based on the different experiences that family members have with regards to their religion and the shared religious beliefs that exist to either stigmatise Dementia or to encourage a collectivist culture. To also ensure that the researcher avoided any misinterpretations, information that appeared inconsistent or vague was clarified with the research participants in order to obtain the participants' ways of constructing their experiences, in a holistic and accurate manner (Merriam & Tisdell, 2016).

Whilst collecting data, through the semi-structured interviews, the researcher made use of field notes with regards to verbal and non-verbal cues that were prominent in the interview processes to draw back on when analysing the data.

3.5.4 Sampling Method

Prior to identifying a sample for data collection, a population needs to be defined in order to draw a sample from that population (Monette et al., 2011).

The definition of a population consists of four things, namely:

Firstly, the content of the population: in this research study, the characteristics that is unique to everyone within a population, whereby, there is commonality. Participants chosen for this study shared the same characteristic of being Hindu as well as being informal caretakers for their relative who is/was diagnosed with Dementia of Alzheimer's type. Furthermore, to ensure a representative sample – their relatives who have been diagnosed were required to be/have been in either the moderate or severe stage of the neurodegenerative disorder.

Secondly, the unit of analysis (the who or what): in this research study, the unit of analysis pertains to Hindu family members.

Thirdly, the geographical area for the population sample that was drawn from: in this research study, the research was conducted in two highly urbanised cities, namely, Pretoria and Johannesburg within the province of Gauteng, South Africa.

Lastly, the population specified the time factor which refers to an appropriate time period whereby specific characteristics are met. In this research study, the family members are/were informal caretakers of their relatives diagnosed with Dementia of Alzheimer's type, during the moderate and severe stages of the disorder.

After the population was identified, a sample was extracted from that population. A sample in research refers to extracting a group of people, objects and/or items in order to perform measurements of specific unanswered phenomenon (Bhardwaj, 2019). To acquire the sample, sampling techniques were implemented by the researcher. A sampling technique refers to the method that is utilised when selecting a group of people, objects and/or items (Bhardwaj, 2019).

The researcher employed a purposive sampling technique to identify and recruit participants for this study. Purposive sampling involves a strategy that ensures specific information is to be extracted from a specific population that are in line with the aims and the objectives of the study (Bywaters et al., 2020).

When considering the number of participants needed for a qualitative research study, six – eight participants are needed when conducting a study amongst a sample that consists of a homogenous group (Holloway & Wheeler, 2010). Furthermore, Bruce et al. (2006) support this finding conducted in a study by Holloway and Wheeler (2010). Bruce et al. (2006) reported that smaller sample sizes in qualitative studies provide rich in detail information that requires thorough analysis. This research study recruited eight research participants, who reside within the Gauteng province in South Africa due to the sample population all sharing similar traits or characteristics (homogenous) of being Hindu and living with and caring for a relative who is/has been diagnosed with Dementia of Alzheimer's type.

The researcher identified the following criteria, which was utilised when recruiting participants for the study:

- Participants needed to follow Hinduism as a religion.
- Participants were required to be a relative of a diagnosed Dementia of Alzheimer's type patient who has resided with the participant for at least 6-12 months.
- Participants, who are relatives to the diagnosed Dementia of Alzheimer's type patient, were required to provide informal caregiving towards the diagnosed patient.
- Participants were between the ages of 30-60 years of age.
- Language was an inclusion criterion as participants are required to be proficient in English. Utilising a translator may have been ineffective due to the fact that 'Indian English', which was introduced by indentured labourers and immigrants migrating to Kwa-Zulu Natal in 1860, started to evolve (Lanham, 1996). As a result, Indian English has now moved away from the influence of Indian languages (Hindi, Tamil, Telegu, Gujarati, for example) and progressively shifted to English as first-home language in many Indian households (Lanham, 1996).

3.5.5 Data Analysis

The aim of the analysis process is to identify reoccurring patterns of responses which are then divided into themes. This is known as thematic analysis.

Braun and Clarke (2022) define thematic analysis as "a method for identifying, analyzing and reporting patterns within data". There are six phases of analysis that the researcher is required to use when analysing data. One of the main benefits is that it is considered a flexible and useful tool used for research in the discipline of Psychology.

The six phases of analysis identified by Braun et al. (2022) which were used by the researcher, see figure 3.1:

Phase one: Awareness of the data: The researcher immersed themselves within the data, ensuring that they became familiar with the content. In doing so, the researcher was involved in reading and re-reading the data. Thereafter, the researcher vigorously analysed the data and looked for patterns in the data – to provisionally formulate themes before moving onto the coding process (Braun et al., 2022).

Phase two: Coding the data: In this phase, the researcher coded the data according to distinct features (semantic or latent). The coding process was done systematically, firstly by assessing the entire set and thereafter, identifying categories for the data which relate to the different codes.

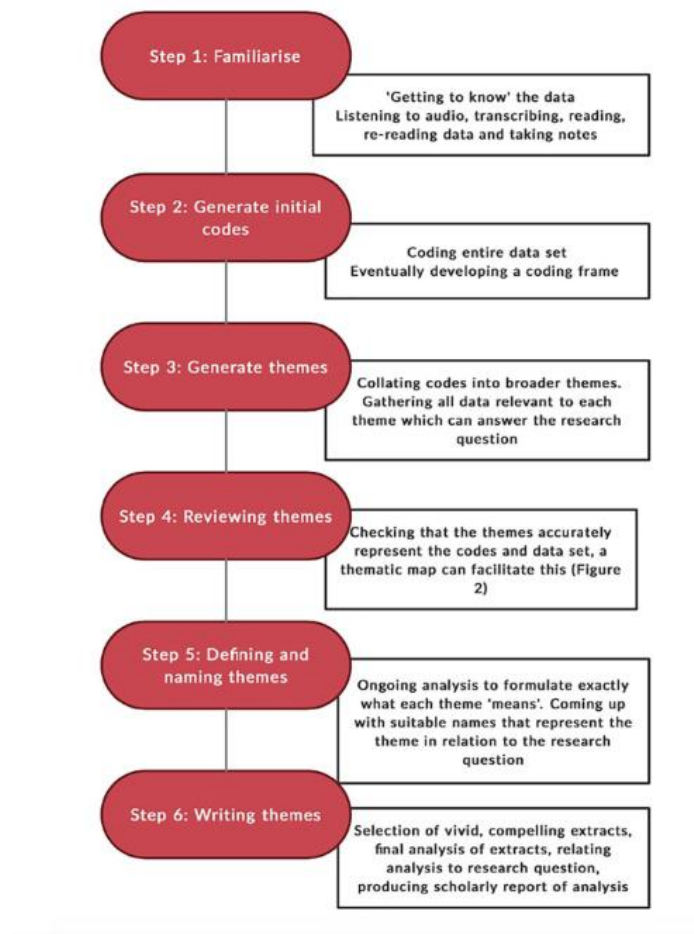
Phase three: Identifying and examining themes: During this phase, the researcher sorted the codes into the potential themes before organising the data into the identified themes.

Phase four: Reviewing identified themes: There are two levels of reviewing and refining the themes in this phase. The researcher read the code the data extracted before reading it again and relating it to the entire data set to ensure that the data was coded and accurately analysed according to its relevant theme.

Phase five: Defining and refining themes: The researcher established what each theme entailed and analysed how the data related to each theme.

Phase six: Generating the report: The final phase of the analysis involved the researcher, generating a full set of identified themes relevant to the data. Thereafter, a thematic analysis was documented by interpreting the data for it to have credibility and merit (Braun et al., 2022).

Figure 3.1 Braun and Clarke's Six Phases of Thematic Analysis (Gee et al., 2021, p. 5).



3.6. Ensuring Rigour and Trustworthiness

The research intends to ensure rigour by ensuring the data gathered was credible.

Rigour, also referred to as trustworthiness are considered key ethical considerations within qualitative research (Creswell, 2009). As cited in King and Stahl (2020) researchers Guba and Lincoln (1985) stipulated that there are criteria that exist to compare against quantitative research, when conducting a qualitative study.

The concept of trustworthiness in research, refers to the process that the researcher adopts in order to ensure that the findings obtained from the research conducted, are dependable and

relevant (Moules et al., 2017). Lincoln and Guba (1985) cited in Moules et al. (2017) introduced criteria to further define trustworthiness. Criteria such as “credibility, transferability, dependability, and confirmability” were introduced in order to contrast with criteria of validity and reliability that is utilised in quantitative research studies (Moules et al., 2017, p.3). To ensure that trustworthiness is maintained within the study, the researcher prioritised being aware of their potentially unhelpful subjectivity when collecting data to avoid contaminating the data collection process.

3.6.1 Credibility

The criterion of credibility ensured that the findings of the study were congruent with that of what the researcher found when collecting data (Shenton, 2004). This is an important aspect of qualitative research studies. The researcher ensured credibility by being self-reflexive and keeping an audit trail (plan of research idea etc.) to document the various processes that were undertaken (see transferability). The researcher was engaged in the process over an extended period of time and continued to do so until the final research report was compiled (Ahmed, 2024). By observing participants within the data collection process, with regards to their behaviours (non-verbal and verbal) as well as how they respond to the interview questions– credibility was established.

The researcher endorsed an open-minded attitude, by being reflective and ensuring that triangulation (using various resources to validate this studies research findings) were used during the process, to enhance this studies credibility (Ahmed, 2024).

Additionally, I am a clinical psychologist, and I am aware of the process – part of my qualification’s forms part of this research’s credibility.

3.6.2 Dependability

The consistency of the research findings was ensured through the process of demonstration albeit any changes, the researcher communicated these changes as they occurred (Shenton, 2004). The researcher ensured dependability by meticulously documenting the process of data collection and ensuring that any changes are communicated through disclosing the research parameters.

3.6.3 Transferability

According to Lincoln and Guba (1985) the concept of transferability in qualitative research, is applied instead of the concept of external validity which is used in quantitative research. Transferability is one of the criteria for trustworthiness of the study's data (Stahl & King, 2020).

Transferability involves ensuring that the findings from the study can be transmitted to another study by providing thick and detailed description of the study in addition to the methods utilised (King & Stahl, 2020). If another researcher intends to utilise the literature findings or data findings from this study, the researcher ensured that a disclosure statement is clearly stipulated regarding the boundaries of replicating this study.

In order to ensure that the research findings can be potentially replicated to other settings, contexts, or research – it is important to plan the transferability of a study according to three areas: “applicability, resonance, and theoretical engagement” (Stelmeijer et al., 2023, p. 2).

Considering applicability, as noted by Lincoln and Guba (1985) as cited in Stelmeijer et al. (2023) it is important to note that in order for applicability to be possible, the research findings need to be sufficiently described so that it can be applied from one context to another.

In relation to the dimension of resonance in transferability, it is important to ensure that the research findings make the reader feel that they can connect to what the research has found, either viscerally or emotionally (Stelmeijer et al., 2023). This is important because the research study will directly evoke a certain level of familiarity as well as a shared experience when reading the research study (Stelmeijer et al., 2023).

Additionally, the dimension of theoretical engagement involves the ideal that when the research study has been completed, the findings will provide theoretical insight for readers whose understanding of the topic will be enhanced and it will provide other researchers, the opportunity to extrapolate the findings and relate it to their study (Stelmeijer et al., 2023).

To ensure that the research study is trustworthy, Koch (2006) suggested that a research audit trail be utilised by the researcher. The audit trail, similar to that of the fiscal audit trail, involves documenting the various steps that the researcher took with regards to each decision, process, and the selection of participants that was made. By documenting this, according to the six-steps suggested by Lincoln and Guba (1985) as cited in Carcary (2009): Raw data; Data reduction and analysis notes; Data reconstruction; Process notes; Materials related to the researcher's intentions and/or dispositions; and the preliminary development information (p. 16).

By keeping an audit trail, the researcher was able to ensure that the study was grounded in theoretical data and prioritise that the findings or inferences make sense (Carcary, 2009).

3.6.7 Confirmability

Assessing whether or not the data collected is consistent with research from other studies. The researcher ensured that self-reflexivity is practiced by being neutral and reducing unhelpful personal subjectivity by being reflexive regarding their subjectivity in order to avoid data contamination from personal subjectivity (Shenton, 2004). Methods of journaling

as well as supervision, and being in personal therapy, allow the researcher to become more self-aware of his/her personal biases before it contaminates the research study.

3.7. Ethical Considerations

The researcher, who was enrolled as a student Clinical Psychologist ensured and adhere that all guidelines within the Health Professions Council of South Africa's (HPCSA) Annexure 12: Ethical rules of conduct pertaining specifically to the profession of Psychology (HPCSA Professional Board of Psychology, 2008) are followed, throughout the duration of the research process. The following ethical considerations are aligned with the HPCSA's Annexure 12: Ethical rules of conduct pertaining specifically to the profession of Psychology and are consistent with the proposed research study (HPCSA Professional Board of Psychology, 2008).

3.7.1 Vulnerability of the participants

The concept vulnerability sparks debate as whether or not it should be considered as part of a research's ethical considerations. In a study conducted by Bell et al. (2017) Kipnis (n.d.) is cited whereby it is stated that vulnerability is a concept that should be considered when an individual is unable to consent to a study due to their impairments physically and mentally. As a result, 'vulnerability' as an ethical guideline for research is salient. By considering this concept for this research study, the researcher is exhibiting a sense of mindfulness as a means of showing the understanding that some participants are considered to be vulnerable to higher risks in the study. There were no vulnerable participants within this study. The study required participants who are related to a Dementia patient or have worked with one as a patient. Despite this, the participating individuals may have felt reluctant to share certain information with the researcher due to the nature of sensitivity as well as they may be uncomfortable disclosing certain aspects of their experiences out of shame, fear or guilt.

As a result of this, the researcher ensured that all participants are not placed in any vulnerable positions as well as ensuring that all participants are aware of their right to withdraw from the study as participation remains voluntary (HPCSA Professional Board of Psychology, 2008).

3.7.2 Informed Consent

According to Denzin and Lincoln (2011), the focal point of any research study is the aspect of informed consent. The word itself highlights two important elements that a researcher is required to adhere to, prior to conducting research. The word “informed” referring to providing the participants with the relevant information regarding the study, and “consent” which refers to the participant agreeing to participate in the study (Denzin & Lincoln, 2011). It is seen as the contract that exists between the researcher and the participant. The HPCSA’s Annexure 12: Ethical rules of conduct pertaining specifically to the profession of Psychology (HPCSA Professional Board of Psychology, 2008) stipulates that when a psychologist conducts research and obtains informed consent, using a language that the participant is able to understand is significant (p. 4).

For the purpose of this research study, the researcher ensured that participants who are proficient in English and are thirty years old and older, were recruited to participate in the study. Prior to participants receiving an informed consent form, participants were required to have the mental and physical capacity to consent (HPCSA Professional Board of Psychology, 2008). Participants were provided with an informed consent form (Appendix D), whereby all the necessary details of the study such as what the expectations of the study are, how the data extracted from the study are stored and utilised as well as any potential consequences regarding the study (Flemming, 2018).

3.7.3 Confidentiality

The confidentiality of this study is an important aspect of ethical considerations made by the researcher. Participants require a sense of privacy as it is their fundamental human right. The HPCSA's Annexure 12: Ethical rules pertaining specifically to the profession of Psychology (HPCSA Professional Board of Psychology, 2008) stipulates that in order to maintain confidentiality between the researcher and the participant, permission from the participant is required first. The researcher ensured that prior to conducting research, permission to record each participant's interview was obtained. Furthermore, the researcher also obtained permission from each participant regarding the outsourcing of third parties to transcribe the interviews as well as to edit the research study. Both, the transcriber, and editor adhered to a non-disclosure agreement ensure that participants' information and interviews are confidential (HPCSA Professional Board of Psychology, 2008).

Therefore, the participants' identities were safeguarded (Strydom, 2011). Anonymity and confidentiality was ensured by using pseudonyms for the participants when the research study was completed, and the research data was analysed for the purpose of answering the questions that the study aims to explore (Strydom, 2011).

The researcher ensured that in order to maintain the participant's confidentiality all personal information relating to the participant and the data obtained, was secured on a password protected device, under a password protected folder. The device was stored away safely in a locked desk draw, whereby only the researcher had access to the device.

3.7.4 Right to Withdraw

The autonomy and respect for participants refers to treating all participants with respect and dignity. Ensuring that all participation remains voluntary and that the participant will not be affected by withdrawing (Terre Blanche et al., 2006). Autonomy and respect was adhered to by the researcher by ensuring a sense of respect and dignity for all participants as well as maintaining that participants were aware of their participation being voluntary.

3.7.5 Non-maleficence

The researcher has a duty to do no harm as well as to avoid potential harm to all research participants. The researcher is responsible for the study and therefore has to ensure that he or she does not increase the risk of exposure to harm. To further ensure that this practice is put in place, this study required approval by the ethics review committee at the University of South Africa. Thereafter, the study was conducted, and all research data was safeguarded on a password protected device and will be stored for at least five years.

Participants were debriefed after participating in the interview as a means of containing any emotions or concerns that may have emerged during the interview process. Participants who required further psychological support and debriefing were referred to a designated independent Clinical Psychologist, whereby services offered were free of charge (Appendix F). No participant required the debriefing services offered.

3.7.6 Gatekeeping

The notion of gatekeeping as an ethical consideration for this study, is implemented as a result of the fact that accessing specific information regarding participants from organisations such as Dementia South Africa (Dementia SA) as well healthcare workers may appear challenging. Due to the Protection of Personal Information (POPI) Act (4) of 2013, the adherence to the protection of an individual's personal information was implemented. As a result, the researcher accessed a mediator within Dementia SA after the mediator read

through the information letter provided (Appendix A) as she had the power to assist the researcher in accessing the relevant and required information. The gatekeeper is considered to be someone mediates between the researcher and the participant in order to obtain specific information surrounding participants (Andoh-Arthur, 2019).

3.7.7 Self-Reflexivity

Self-reflexivity in research, refers to the preconceptions, biased beliefs, and attitudes that the researcher may hold in a personal capacity which can influence specific decisions and behaviour whilst research is conducted. As a result, this may affect the way that the researcher makes decisions pertaining to the study such as choosing specific questions to questions for the interview (Adkins et al., 2020). In addition, the researcher uses self-reflexivity as a tool to reflect on their subjective experiences that may be triggered during the research process. This helps to reduce the subjective bias contamination during the research process.

As cited by Smith (2006), Smith (1987) also elaborates on the concept of self-reflexivity. Smith (2006) highlights that a researcher needs to be aware of their 'self'. This is important because it helps to ensure that the research conducted, is not only qualitative in nature, but also that it is realistic. Researchers, Merriam and Tisdell (2016) highlighted the significance of the researcher being the most important tool in the research process. Due to the fact that both the researcher and participants have their own experiences, opinions, and beliefs around a certain phenomenon – the manner within which they interact with one another during the interview process cannot be neutral (Morrison, 2015).

The nature of the relationship between the researcher and the participants is one that according to Miller (2000) should not only be concerned with obtaining data but rather a social interaction, whereby the way and manner that the researcher contributes to the process is equally as important as that of the research participants' contributions.

Being aware of the researcher's subjectivity is salient in this process but it requires more than awareness in terms of implementing a process to support one's awareness (Haynes, 2012). In doing this, journalling and documenting the researcher's personal biases and experiences throughout the interviewing processes, was elaborated within the researcher's field notes as well as within her research supervision. To further account for the researcher's awareness of their personal biases, a method of bracketing was used. This was ensured to avoid any preconceived ideas or beliefs that the researcher had during the interview, to allow for a more focused process – whereby the experiences of Hindu family members' remained central to the process (Maitra & Weatherford, 2019).

Methods of journaling were implemented to keep the researchers experiences with her grandfather's diagnosis, separate from the experiences shared by participants which is known as bracketing. Further emphasis was placed on the researcher's constant process of being self-reflective and was engaged with his/her supervisor regarding any potential blind spots.

3.7.8 Ethical oversight

This research dissertation adheres to the guidelines, policies and procedures implemented and stated by the University of South Africa. This paper was submitted to the ethics review panel within the Department of Psychology at the University of South Africa, as mentioned above, in order to obtain permission to carry out the study (Appendix A).

3.8 Limitations of the Study

A significant factor to consider that limits the study, refers to the aspect of available literature within the South African context. There is minimal research that has been previously conducted on Hinduism and Dementia simultaneously within the South African context. Furthermore, due to the stigma surrounding the neurodegenerative disorder, accessing family members was challenging – especially those family members who are concerned about their community's beliefs.

In addition, the sample that was intended for this study may pose as a sample bias as the sample is not reflective of all Hindu families, healthcare workers and the broader Hindu community who live and work with an individual who is diagnosed with Dementia of Alzheimer's type.

Chapter 4: Findings and Discussion

As individuals age, the likelihood of a Dementia diagnosis increases, this is often accompanied by a progressive decline in their ability to care for themselves independently (Tung et al., 2018). Existing literature highlights that apart from the burden and strain experienced by caregivers who provide care for a Dementia diagnosed individual, caregivers have also reported that they are often expected to make “a lot of sacrifices” (Srivastava et al., 2016, p. 134). As a result, it remains important to understand these sacrifices within a cultural and religious context (Srivastava et al., 2016).

This chapter presents the findings of the present study, which aimed to explore the experiences of family members who are informal caregivers providing care to their relatives diagnosed with Dementia of the Alzheimer’s type within a Hindu context in South Africa. Consistent with a qualitative research approach, the findings are rooted in participants’ experiences and the meanings they construct around their caregiving roles.

The findings that are presented in this chapter reflect that informal caregiving, provided by family members, is a complex and multidimensional layered process. Through Braun and Clarke’s (2006) thematic analysis, the following themes emerged: The Stigma, Role Reversal, Spiritual Beliefs as Coping Mechanisms, Access to Specialised Care, Family Support, Individualistic and Collectivistic Beliefs, Retrogenesis, and Caregiver Tracking of Symptoms. These themes, highlight that the caregivers experiences resemble an interplay between psychological, cultural, relational and systemic factors.

Both spiritual and cultural belief systems held by participants’, emerged as central themes that demonstrated the processes as to how family members, providing informal caregiving, make meaning of their experiences through concepts such as karma, reincarnation, and

spiritual caregiving. These concepts also appeared to shape how family members identified the cause of their relatives' diagnoses with Dementia of Alzheimer's type as well as how as caregivers, these concepts were also used to cope with the strenuous demands of care.

In line with this, the findings suggest that the caregiving process extends far beyond a physical experience and instead, encompasses processes that are deeply rooted in culture, relational, and psychological processes.

Table 4.1 below presents the demographic characteristics of the participants included in the study. It provides an overview of key information such as age, gender, relationship to the diagnosed relative, and other relevant background details.

Table 4.1 Demographics of participants living in South Africa.

Participant	Age of Participant	Relation to the Diagnosed Relative	Home Language	Ethnicity	Religion	Years Diagnosed	Stage of Dementia
1	51	Daughter	English	Indian	Gujarati	3 Years	Moderate
2	49	Daughter-in-Law	English	Indian	Hindi	1 Year	Moderate
3	42	Daughter	English	Indian	Tamil	3 Years	Moderate
4	53	Daughter	English	Indian	Hindi	8 Years	Severe
5	50	Son	English	Indian	Tamil	3 Years	Moderate
6	52	Son	English	Indian	Tamil	2 Years	Severe
7	47	Daughter	English	Indian	Hindi	2 Years	Severe
8	55	Sister	English	Indian	Gujarati	1 Year	Moderate

Table 4.2 below provides an overview of the themes and sub-themes identified from participants' narratives using Braun and Clarke's (2006) Thematic Analysis. This table provides an organised overview of the key patterns and recurring ideas expressed by participants regarding their experiences of informal caregiving for relatives diagnosed with Dementia of Alzheimer's Type.

Table 4.2 Highlighting the themes and sub-themes that were identified using Braun and Clarke's (2006) Thematic Analysis, within the participants' narratives.

Themes	Sub-themes
<i>The Stigma</i>	1. Denial and Shame 2. Religious reframing 3. Avoidance of Dementia – Related Difficulties
<i>Role reversal</i>	1. Lifestyle Changes 2. Psychological Burden 3. Loss of Parental Identity
<i>Spiritual beliefs as coping mechanisms</i>	1. Karma 2. Reincarnation 3. Spiritual Caregiving
<i>Access to specialised care</i>	1. Lack of Knowledge 2. Barriers within the System
<i>Family Support</i>	1. Family support vs. Professional Services

Individualistic Beliefs

Collectivistic Beliefs

1. Familial Duty and Sacrifice
 2. Sensitivity Towards Relative
-

Retrogenesis

Caregiver Burnout

Caregiver Tracking Symptoms

1. Confabulation
-

The following section presents the themes and sub-themes identified from participants' narratives using Braun & Clarke's (2006) Thematic Analysis. These themes highlight the key experiences and perceptions of Hindu families providing informal care for relatives diagnosed with Dementia of Alzheimer's Type. The themes encompass the emotional, psychological, spiritual, and practical aspects of caregiving, including experiences of stigma, role reversals, the use of spiritual beliefs as coping mechanisms, access to specialised care, family support, cultural belief systems, and caregiving challenges related to retrogenesis and symptom tracking. Each theme is further divided into sub-themes to highlight the nuanced ways in which participants navigated caregiving responsibilities within the context of their cultural and religious values.

4.3 The Stigma

The following theme is discussed below, in order to conceptualise the stigmatised experiences that were reported by participants.

In a research study conducted by Andersen et al (2022) titled: *“On the Definition of Stigma”* it was noted that the word ‘stigma’ has been widely researched and defined by multiple researchers.

It’s meaning is said to be determined based on the context within which it is used (Andersen et al., 2022). Within clinical settings, the stigma that is placed on individuals with a diagnosis are perceived as “incompetent, weak, and dangerous” (Štrkalj-Ivezić, 2013, p. 202).

It is defined as a form of prejudice or stereotype that is unknowingly placed onto a group or an individual (Abu-Snienh et al., 2018).

Stigmatisation is the process whereby the individual who is being stigmatised is further marginalised from society (Parcesepe and Cabassa, 2013).

4.3.1 Denial and Shame

Some participants narratives revealed that there was an initial stigma. The stigma identified appeared to be an internalised form of stigma on behalf of the participant themselves. This stigma appeared to also present within the family context as a form of reluctance to provide caregiving from other family members. Participant six revealed that with the stigma present, pity for the caregiver was not wanted, possibly revealing that the manner within which he was engaged with – made him feel that others felt a form of pity towards him. In a manner that wasn’t genuine but rather one that led him to feel ashamed:

“There was initially a little bit of stigma... you don’t want that pity”.

Similarly, participant two shared the indiscrete stigma she observed within her family regarding institutionalising her family member who was diagnosed with Dementia:

“The aunt... didn’t tell the family about it. I think the reason they didn’t was how the family would react to her putting the mother in the nursing home.”

In most Hindu collectivist groups, any form of illness is perceived as failure on behalf of the family – with regards to the person who is “ill” (Shaij et al., 2003). This is because the individual and the family are considered to be deeply embedded as ‘one unit’. As seen in participant six’s response, it should be noted that any form of pity toward the caregiver is not wanted as according to Ahad et al. (2023) stigma is often associated with a negative stereotype.

This often leads to an individual feeling that they are marginalised from a community or being prejudiced against. In line with the above, participant six further reported a form of prejudice against a decision he had made for his relative to reside with him. Noting the responses he received, and how difficult those around him – told him it would be:

“Look, initially when I built this place and I told my siblings and also some of my cousins, and they said, ‘guy, bad idea. It’s not going to work’”.

Similarly, participant one shared a similar experience. She noted that the stigma she encountered was internal, bringing forth a different form of ‘shame’:

“I think there was initially a little bit of stigma around it, but not to the extent that I couldn’t share it. And it wasn’t so much being a Hindu where the stigma came, but I think I am part of a family that’s quite, what’s the word, progressive in the thought”.

Participant one’s response also corroborates what Shalaby et al. (2025) reported in their research study. Highlighting that the stigma placed onto patients and healthcare workers around mental illnesses or health disorders is also felt by the patients relatives too (Shalaby et al., 2025).

Whereas participant seven highlighted the external response received, that appears to initiate a form of fear as well as perpetuate the stigma:

“A lot of people tend to think that if you’ve got Dementia, something’s severely wrong with you”.

Parker et al. (2020) reported that the stigma associated with Dementia is seen as a barrier to acceptance within families.

4.3.2 Religious Reframing

Participant five – “they said ‘let’s just pray, it’ll pass. They didn’t want to believe it was medical”.

Based on the above response, it is evident that religiously reframing the stigma around Dementia is something that does still exist within collectivistic cultures. It appeared that any discussion around mental illness may highlight the shame that extended family members may be feeling. According to Goffman (1963) as cited in Andel et al. (2013) stigmatisation leads to an individual who has been stigmatised experiencing a form of internalised stigma whereby certain beliefs - similar to those who are stigmatising - are held (p. 5). In relation to the study, it appeared that the identity formed around Dementia is not only on an individual level, but also on a community level.

4.3.3 Avoidance of Dementia - Related Difficulties

Considering Murray Bowen’s theory of Family System’s therapy, an individual is not an entity that exists on its own (Brown, 1999). Instead, how an individual functions – is dependent on the functioning of their context (their system). Systems that are able to adapt to an individual’s process of individuation, while still being connected to the family, and are able to establish boundaries that are not fused are considered healthier families (Brown, 1999). Whereas, families that aren’t able to adjust to fusion or change within the system are

seen as being dysfunctional. Linking this to how the Family Systems Theory perceives dysfunction within a systemic context, in line with the stigma around Dementia, there appears to be a tendency to avoid the dysfunction the disorder may cause in order to maintain the family's equilibrium (Bowen, 1978). Participant five described the difficulty of being able to confront the challenges of looking after a diagnosed relative and instead avoiding the difficulty:

“You’re trying at all times to be completely respectful, but when someone is not listening to you, is having temper tantrums, shouting at you... yeah”

This further highlights the communication challenges of caregiving for a Dementia patient, which further leads to frustration on behalf of both individuals. Due to the diagnosed individual not being able to communicate nor understand any communication (Abdelkader et al., 2024). Later on resorting to outbursts (temper tantrums and shouting at relative) as a means to ‘communicate’.

4.4 Role Reversal

From a Psychological perspective the concept of ‘role reversal’ is used as a therapeutic tool in the context of therapy (Bhaumik et al., 2024). However, in the context of this study it is intended to help an individual enhance their sense of empathy as well as to improve their emotional understanding (Magalhães et al., 2023; Wu et al., 2025). On the contrary, in relation to the findings of this study the aspect of role reversal is done unknowingly and does not enhance an individual's empathy towards another. Instead, it appears that the reality of role reversal in caregiving is to ensure that effective caregiving is provided.

Within an Ecological Systems Theory framework, the concept of role reversal can be understood as a process of adaptation that occurs at a microsystemic level within a level in

order to meet the demands of caring for a relative diagnosed with Dementia of Alzheimer's type. Taking this into consideration, role reversal immediately demonstrates a change in roles within a system. This change of roles shapes how the caregiver provides care, as it removes the caregiver from their previous role to a newly defined one – based on cultural expectations, family expectations, and the needs from the diagnosed individual.

These role changes are influenced by interactions across multiple system levels, including familial expectations, cultural norms, and broader social and structural pressures that shape caregiving capacity. In this sense, role reversal represents a reorganisation of family roles driven by environmental stressors and caregiving needs, rather than a therapeutic process aimed at improving interpersonal understanding.

From a Family System's perspective, one would argue that 'role reversal' within the narratives in this study can be seen as a form of Parentification. Parentification occurs when a child takes on the responsibility to care for their parent (Borchet et al., 2021).

As seen with participant two who described the filial piety that was placed onto her by her religion.

“As Hindus, we are supposed to look after our elderly people...”

Furthermore, participant one shared the difficulty of role reversal, highlighting the emotional experience she has had.

“Our roles became completely reversed, where I started taking care of her... she's latched onto me a lot and that created a lot of pressure on me.”

Additionally participant five shared a similar sentiment:

“it's a difficult one because as much as you conditioned and you know what your responsibilities are, it was actually very frustrating because there's a line that you do not

cross when it's your parents you know. No matter how they behave you're always very respectful and it started off you know on a good note but very quickly the roles became reversed. I felt very much like the parent and constantly having to almost reprimand but then not quite reprimanding".

Participant five further noted:

"Taking on a parent role for a parent is I think very frustrating, very challenging also because you're trying at all times to be completely respectful but when someone is not listening to you, is having temper tantrums, shouting at you - it just yeah - it just became completely difficult".

However, within the context of this study, the experience of role reversal as seen above is multifaceted. It can be perceived as either of the above – placing emphasis on the idea that participants were forced to change their roles by means of sacrifices or making changes in their lives in order to provide informal caregiving for their Dementia of Alzheimer's type relative.

4.4.1 Lifestyle Changes

All of the participants narratives revealed that their lifestyles changed. It appeared that these changes were imperative in order to carry out the caregiving process. Changes such as having to restructure day to day activities, living arrangements within the household, and the role of caregiving. Participant one highlighted the role reversal of having to make changes in order to accommodate for the diagnosed relative:

"Our roles became completely reversed, where I started taking care of her... I had to prepare her for when I was leaving the house because she'd become very anxious if I wasn't there".

Supported by preceding research conducted by Marques et al. (2023) who highlighted that the individual who is diagnosed, was the individual who initially provided care, however due

to their diagnosis and decline in functioning – the person who received the care, is now the one to provide it. Supporting this, participants revealed that their parents’ appeared to be regressed as seen by participant five:

“It affected everyone’s quality of life and so yeah it’s just been a little bit of a shock to the system. I think quite a big disruption to kind of the plan that we had where she would stay with us for as long as possible or we would have a caregiver you know at home here for her. But then also at the same time weighing out how much all of this is going to cost and trying to find a solution that’s you know best for her, so yeah, I think it was just a shock for everyone that it was so rapid, it was unbelievably rapid”

4.4.2 Psychological Burden

According to Franza (2019) psychological burden is defined as “an excessive reaction to stress caused by one’s environment that may be characterised by feelings of emotional and physical exhaustion, coupled with a sense of frustration and failure” (p. 38).

In line with this, most participants narratives suggest that despite the cultural expectation of needing to take care of their elders, the underlying stress and physical exhaustion was intense. Participant six revealed that the act of caregiving led to conflict between him and his father who was diagnosed with Dementia due to the overwhelming feeling of guilt, emotional exhaustion and fatigue the caregiving caused:

“I ended up fighting with him... I just couldn’t take it anymore. It was like looking after a baby, but worse”.

Similarly, participant one highlighted that their experience of caregiving for one’s loved one led to their experience of anxiety, which led to the caregiver resorting to seeking psychotherapy for themselves:

“It was really difficult on my own mental health. I started seeing a Psychologist”.

The expectation that is placed on family members to provide informal caregiving for their relative, has negative consequences upon the caregiver's health (del-Pino-Casado et al., 2021). Furthermore, it has been reported that providing informal caregiving is likely to result in a psychiatric disorder, with anxiety being the least studied disorder despite it being the most prevalent mental health disorder amongst family members who provide informal caregiving (del-Pino-Casado et al., 2021). It is worth noting that seeking professional help as the caregiver in an attempt to reduce the psychological burden, is significant, as in the case with participant one.

In similar research studies conducted, it is significant to note that the well-being of caregivers were compared to individuals who do not provide any form of caregiving. In the comparison, it was highlighted that caregivers revealed a greater usage of psychological and psychotropic medications as well as reported higher levels of anxiety (Schulz & Williamson, 1994).

4.4.3 Loss of Parental Identity

Participants whose parent were the diagnosed relative, revealed the difficulty around witnessing their parent 'lose' their identity as a parent. Participant four described the emotional difficulty of no longer being able to relate to her parent with Dementia as a mother:

“The thought of my mom being alive, but the person I knew to be my mom was no longer there”.

The loss of the parent in terms of their role is defined by Boss (2016) as a form of ambiguous loss, also known as psychological loss, which refers to a process whereby an individual is “physically present but psychologically missing due to a cognitive impairment or memory loss” (p. 270). This type of loss is difficult as it involves a grieving process that is not common to society.

The type of grief that is experienced from an ambiguous loss is more related to the idea that, the person is alive and that their disorder has changed them. Whereas, with death, the loss is physically permanent and it is reported to be a process that is easier to mourn from. Whereas with ambiguous loss, common in Dementia bound families, there is a hold that is placed on relationships. For example, as mentioned in the *role reversal* theme above, ambiguous loss is experienced hand in hand with this. Consider a child who is no longer able to relate to their mother as a mother, but instead has to ‘grieve’ the loss of their mother’s maternal care and instead – provide care, to a regressed form of a child.

Similarly, participant five shared that with the ambiguous loss, it is often coupled with challenging roles which are reversed.

“As much as you’re conditioned and you know what your responsibilities are, it was actually very frustrating because there’s a line that you do not cross when it’s your parents... but very quickly the roles became reversed. I felt very much like the parent and constantly having to almost reprimand but then not quite reprimanding.”

In addition to psychological loss, participant five revealed that the loss one experiences takes on a process of mourning despite the person being mourned being alive still:

“It’s like she’s a body without a soul. The essence of who my mother was is completely gone”.

This phenomenon described by participant five is known as ‘anticipatory grief’. In a research study conducted by Blandin and Pepin (2016), herein, it was noted that prior to the physical loss of the relative who has been diagnosed with Dementia, family members experience what is known as Dementia grief.

Dementia grief is defined as “A specific type of anticipatory grief in response to compounded serial losses of varying magnitude and marked by the ambiguity that characterise the experiences of loss in Dementia” (p. 3).

4.5 Spiritual and Religious Beliefs as Coping Mechanisms

Due to the difficulty of accepting as well as caring for an individual diagnosed with Dementia of Alzheimer's type, it was noted that most participants relied on their spiritual and religious beliefs as coping mechanisms.

According to Brandão and Graça (2024) this process is understood as “using cognitive and behavioural strategies based on an individual's beliefs and values to deal with stress” (p. 343) which is said to improve the individual's well-being as well as their satisfaction with life.

Participant four shared the religious practice and significance of using a religious worshipping song, such as the Hanuman Chalisa which in Hinduism is known as a bhajan. Playing the Hanuman Chalisa appeared to be used as a coping mechanism. Participant four described how this was implemented as a form of a coping mechanism for both her relative who was hospitalised.

“She was a Hare Krishna devotee... so most of the bhajans I used to play were Krishna bhajans for her... even when she was in hospital, I'd play the Hanuman Chalisa.”

Research by Shoba (2024) demonstrates how the 40 versed hymn “serves as a powerful hymn that promotes strength, mental well-being and leadership qualities, with potential benefits such as reduced blood pressure and improved mental health” (p.2).

There are two types of coping: positive and negative spiritual coping. However, within the narratives analysed, it appeared that the coping was based on the participants interpretations of certain life events seen as a ‘divine retribution’ i.e., Karma and Reincarnation (Brandão & Graça, 2024). This is considered as negative spiritual coping.

Participant six shared his belief regarding his father's diagnosis, linking it to reincarnation and how everything has interconnected meaning:

“I think when we’re all born, we all reincarnate, I think, in my opinion, I think we all reincarnate of a previous life. I do believe that we have been around for maybe hundreds of thousands of lives, maybe less, I’m not sure. But I do believe that we are all a form of energy, and this energy can never die, it can just evolve and go on to different levels, I’m not sure what the end product would be, or maybe we join up with something like the sun, that’s energy. Yes, it is part of my dad’s karmic energy”.

4.5.1 Karma

Most of the participants’, in the current study, expressed that it is part of their ‘Karma’ to provide caregiving to their diagnosed relative. Linking their experiences with providing care and the challenges thereof to what they have identified as their ‘Karmic cycle’. It was highlighted that some participants’ believed that part of their ‘Karmic cycle’ involved being able to take care of someone else, and despite the challenges faced, it was imperative to have a ‘corrective’ experience by being a moral individual who is attuned to caregiving for a family member. This was noticeable in participant five’s response:

“I never thought I’d end up caring for him like this... but, maybe, I must have done something to deserve it”.

Moreover, participant five also notes that there are consequences to one’s actions. Outside of the notion of karma, there is the belief that what is destined for you – will be part of your fate:

“I can say certainly for mom who had to take care of my gran that there was that strong belief that this is not something that is purely a medical issue. It’s just the fact that it’s what you’ve done in your past life and your sins. So you’ve got to obviously pay for that before you move on to you know your next life. So this concept of suffering is something that one should

accept because that is your fate and it was what is destined for you. Therefore there's nothing you can do about it"

In a research article titled, *'In pursuit of good karma: When charitable appeals to do right go wrong'*, it was highlighted that a large number of individuals have a belief system that is built on the idea of the universe rewarding one for one's good deeds and punishing one's for one's bad ones (Kulow & Kramer, 2016). This also highlights the internalised belief that participant five may be holding with regards to why the process of caregiving is their responsibility.

It became evident after analysing the participants' narratives that there is a process of reframing the burden of caregiving, as a form of karma bestowed upon the caregiver.

Participant three appeared to be conflicted and disappointed as he described the sacrifices his mother had made for her own parent who had Dementia, and despite this, they were still diagnosed with Dementia. He expressed the emotional difficulty of this as he questioned why his relative has to suffer:

"My mom took care of my gran who had Dementia... then a year later, she's diagnosed with it. She sacrificed all that time. We always believe that the more you pray and help, the better your life will be... but now she can't enjoy her retirement".

Furthermore, it is worthy to note that despite believing in karma, participant three also holds a belief that karma is not the only causal factor. Instead, he believes that in line with the biomedical model – there is science to justify the neurodegenerative disorder.

Additionally, using religious concepts as a coping mechanism also signifies the plea of requiring urgent assistance, as noted by participant five who demonstrated that believing in the concept of karma in relation to her relative's diagnosis, was implemented as a means of understanding the reasoning behind one's suffering and how to promote a better reincarnated life:

“Even with my mom before she got seriously bad she would say it repeatedly “it’s my karma and I have to deal with it”. I think that plays a massive role because there’s always that belief that you have to suffer in order to have a better life in the next life”.

In addition to this, it appeared that participant five and participant eight attempted to justify their hardship while being informal caregivers for their relatives. Participant five attributed his caregiving process to the values instilled in him as a child:

“We have this very strong sense of caring for our parents... that’s what is instilled in us growing up, that you always put your family first”.

Similarly, participant eight described the religious process her relative would rely on:

“He goes into the prayer room, sits and prays for about half an hour, then comes out and tells us he’s prayed for us”.

In line with what Xu et al. (2019) have suggested, that if an individual believes in karma – their life may have more meaning and a purpose. This is supported by what participant one shared in terms of how she made sense of her relative’s diagnosis:

“So without a doubt, her previous activities have led to the life she’s leading now, the life she led even before she was diagnosed. So I wouldn’t say it’s neither an uncomfortable nor a comfortable thought. It’s just, it’s an acceptance that that’s where she’s at. And, all we have to do is make the best of a bad bargain with her and to help her, perhaps in the next life, to help readjust that karma for her own sake”.

Similarly, Pakad (2024) reported that the awareness of our good deeds is a form of personal growth. Resulting in a more positive experience within our personal lives – in the future. Further highlighting that, “When we strive to act in ways that benefit others, we not only

contribute to a more harmonious world but also create positive karma for ourselves” (Pakad, 2024, p. 42).

4.5.2 Reincarnation

Only one participant held a belief that part of their relative’s diagnosis was due to the concept of reincarnation. Participant eight shared her belief and spiritual insights when meeting a stranger, who had confirmed her relative was reincarnated to fulfil their duty:

“I believe this is his last life on earth and not just from my reasoning or from my understanding of how the universe works. We’ve had a lot of spiritual insights. We had a stranger we met once that was doing this natural healing and very highly acclaimed in his religious and sort of astronomy type things, right! And, when he met us, he said to us, ‘he’s come back just to finish one aspect of his soul journey and this is his last birth’.”

A religious concept within Hinduism, reincarnation, describes that an individual’s soul is reborn into a new body, animal, or spirit – which according to Nagaraj et al (2013) posits that the next life you are born into, is solely dependent on your karma as noted by participant five:

“Everything’s about karma - it’s you accept suffering because it’s a consequence of this whole life that you have, right! And, so if you want to be reincarnated into a better form then you have to endure the suffering”.

Therefore, reinforcing that participant eight and five both believe that their diagnosed relative was reincarnated to correct a previous karmic cycle (Pakad, 2024).

4.5.3 Spiritual Caregiving

Whilst most participants reported that they do not believe in performing any spiritual rituals for their diagnosed relatives, participant four held the belief that spirituality was a form of ‘care’ in terms of how her mother remained connected to herself:

“Whenever she walked into house, the first thing she used to do was walk towards that Ganesha that I have in the front... to offer a prayer to it...”

Similarly, participant one shared:

“We have various of our spiritual masters that come visit us at home and she likes to be part of their preparations when they come home... I give her books to read. Simple, easy to understand books. Like, you know, stories about characters of Ramayana and things like that. Just so that she has an understanding. Whether she'll remember it or not when she puts a book down is a different story, but that's what I like to do. And, then like I told you, she chants all the time. Every day she chants 16 rounds”.

According to Hvidt et al. (2020) the idea behind spiritual care is pivotal. It is defined as a form of care that is based on the dynamic of human life and how individuals are able to “experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to themselves, to others, to nature, to the important and/or the holy aspects” (Hvidt et al., 2020, p. 7).

In line with this, participant four highlighted that despite her relatives diagnosis with Dementia of Alzheimer's type, her relative was able to connect to herself in a spiritual manner – which may provide comfort and emotional resilience to the diagnosed relative (St. John's Dementia Resource Centre, 2024).

Furthermore, according to Winnicott's theory (Litt, 1986) the Ganesha statue may function as a transitional object for participant four's relative by keeping her grounded to her spiritual belief system as participant four revealed that:

“I used to invite her to come and sit... we used to do the prayers together”.

This suggesting that despite the cognitive decline that was apparent, having a ritual may provide a sense of stability for a diagnosed individual.

4.6 Access to Specialised Care

In line with the literature review of this study, the care that is provided to diagnosed patients is specialised. Meaning that it is appropriately chosen in order to effectively treat the individual. Yet, primary healthcare providers such as General Practitioners (GP) are integral role players when it comes to the care of individuals diagnosed with Dementia. The GP is often seen as the “central healthcare provider who coordinates care for their health and social problems” (The Health Foundation Inspiring Improvement, 2011, p.10).

Whereas, secondary care involves medical healthcare providers such as neurologists who provide specific care to Dementia patients. Despite the importance of both primary and secondary care, these services are often underutilised due to: lack of knowledge around the disorder, cultural expectations, stigma, and transport.

Based upon these factors, accessing care is often difficult due to the large prevalence of the disorder. Participant one shared this difficulty around finding a suitable specialist that would guide her and her family with her relative’s diagnosis:

“It’s just a limitation on the number of geriatricians in the country. I mean, I think there must have been about seven or something in Gauteng, which is ridiculous. I mean, you look at the number of all people around and they’re all full, understandable. So, that’s what made it even more, that much more difficult to find somebody to help with the diagnosis”.

Additionally, not only is it difficult to access care – but there is a limit to the type of care one can receive. As well as, at times the provision of care is limited for families who provide informal caregiving to their diagnosed relative due to how the caregiving services are

structured within that family (Malhotra & Ramakrishnan, 2025). Therefore, informal caregivers do not seek out the caregiving services due to the number of barriers.

Additionally, caregivers do not implement any form of formal caregiving due to the financial strain that is carried by the informal caregiving relative (Fan et al., 2023). This was shared by Participant five:

“We had to weight out how much all of this is going to cost and try to find a solution; that’s the best for her. It was such a rapid decline, we had to get her reassessed to get her stronger meds to keep her calm”.

4.6.1 Lack of Knowledge

Four of the participants revealed that they had a lack of knowledge with regards to his relative’s diagnosis. Highlighting the misunderstanding of their relative’s symptoms as well as the possible lack of seeking healthcare assistance, immediately:

Participant one shared her difficulties of not having access to adequate knowledge about her relative’s diagnosis but moreso, the difficulty of not being able to find any form of communal support that would have enhanced her ability to caregive:

“No, I didn’t have enough knowledge, definitely did not have enough knowledge. When it started, when we started seeing the signs, the first thing you go to is Dr. Google, and you go and search. And, then it was like understanding, okay, she does this, she does this, tick the box, tick the box, tick the box, tick the box. Okay, it looks like she does have it. But it was, once I started looking for that information, I found it. But, initially, you don’t have many people, or many sites that are able to provide the training for caregivers. That’s what I didn’t find”.

Whereas, participant five, he shared the difficulty of coming to the realisation that the neurodegenerative disorder is not a slow disease, but rather a rapid cognitive decline:

“I kind of the thought that with my mom it’s a slow disease, she’s not going to rapidly decline. So, we have many years still ahead where she’s fully functional and can kind of fend for herself... only to find that it was such a rapid decline.”

The rapid decline in the neurodegenerative disorder appeared to not be known with participant five, possibly due to their prior family experience or misunderstanding of the disorder.

Similarly, the symptoms that were exhibited were considered by external family members of the diagnosed relative, to be a normal part of aging according to participant three:

“Initially, people couldn’t fathom the concept of her getting confused... like, for example, my aunt, she thought, ‘No, it’s old age’”.

Participant eight also described a passive acceptance and ambivalence around the symptoms she encountered with her relative, due to a possible knowledge gap as well as no medical support in terms of accessing the knowledge:

“Yes, I noticed that my mom went through a small phase... they didn’t classify it or identify it as Dementia, they just said it could be age-related... So, we didn’t expand on that too much”.

Dobrowolski (2014) noted that it is common for people to assume that cognitive decline occurs when one starts to age. However, preceding research has reported that having Dementia is not an inevitable result due to aging, even though aging is considered to be a risk factor for being diagnosed with the neurodegenerative disorder (Dobrowolski, 2014).

This also highlights that due to the age-related assumption around ‘forgetfulness’ which is also seen in Dementia diagnosed individuals – the treatment of the disorder may go undiagnosed and untreated. Furthermore, Potocnik (2013) suggests that any form of Dementia treatment, needs to be holistic and aimed to maximise the functionality and quality

of life for the diagnosed person. Without early detection or any form of treatment – the deterioration may be rapid causing the individual as well as their family a form of suffering.

The findings from these narratives reflect that there is a knowledge gap in terms of how Dementia of Alzheimer's type is understood. Particularly, within the Hindu context, it is significant to note that the gaps of knowledge exist due to attributing the symptoms to factors of spirituality or normalising the symptoms as a form of silencing the reality of the diagnosis.

4.6.2 Barriers within the System

According to Aitken (2020) there are multiple barriers to care for Dementia of Alzheimer's type relative.

In addition to the first theme of 'stigma', there are other barriers to how the disorder is understood which further impact how the disorder may be treated and how caregivers may respond to the disorder.

Considering the barrier of being able to preserve the individual's autonomy due to having to adhere to one's cultural 'duty', most of the participants described their duty to care for their relative informally – as part of what is considered 'normal'. Participant five shared their difficulty of not being able to seek out professional caregiving, due to cultural expectations.

This appeared to serve as a barrier:

“If I had my way, my mom would have been in a retirement home... but, we have this tendency to want to care because ‘you always put your parents first’... to their own detriment, we keep them with us”.

Similarly, participant two and participant eight also highlighted the expectation within Hindu families:

Participant two – “As Hindus, we are supposed to look after our elderly people... I think that’s why the daughter didn’t tell the family about putting the grandmother in the nursing home”.

Participant eight – “As an Indian family... we don’t do care facilities”.

From an Ecological Systems theory, these expectations emphasised above are embedded in the Hindu culture whereby one is expected to ‘fulfil their duty’. This highlights that the cultural expectations that placed onto a caregiver are deeply influenced by the macrosystemic level, whereby the beliefs and culture around caregiving – impact the nature of caregiving. All narratives highlight that due to what is expected of them culturally, they were unable to seek out formal residential caregiving services despite requiring it. The fear of family judgement appears to be a significant factor in why the cultural duty is not argued against.

Supporting this, researchers Chittem et al. (2022) report that within the Hindu belief system, the concept of death is something that is already determined by the divine will of that individual’s life, with an emphasis on whether the individual has fulfilled their duty and Moksha. Moksha refers to a spiritual liberation which is imperative for an individual’s right to experience a ‘good’ death (Firdaus et al., 2024).

It is worth noting, that based on the above, family members of diagnosed relatives – intend to fulfil their duty in the form of spiritual caregiving, in order to create a good karmic cycle, which later on in life leads to the highest attained Moksha (Firdaus et al., 2024).

This is likely why participants’ narratives revealed that despite the challenges they faced on an individual level, direct caregiving of one’s elderly parents is a part of a greater spiritual belief within Hindu families in terms of Karma, Reincarnation, and Moksha – leading to the

caregiver experiencing a more fulfilled afterlife. From an Ecological Systems theory, caregiving is not only seen as a practical responsibility, but rather a spiritual obligation. This obligation may discourage families from seeking professional care due to fear of social judgement or perceived spiritual consequences, for the caregiver.

In addition, Parker et al. (2020) identified financial challenges as well as inadequate structures of support as other barriers impacting the provision of caregiving. These challenges reflect exosystemic influences that prevent the family from seeking professional care, and in turn are forced to provide informal caregiving services. This was extrapolated from participant five's narrative, who described the process of accessing care as something that was difficult due to limited finances:

"We had to weigh out how much all of this is going to cost and trying to find a solution".

Whereas, participant six mentioned the difficulty of not having enough support at home in order for him to provide adequate care:

"We had a helper that would come, but she would leave by four (o'clock). So from then until the night, I would take care of him myself".

Overall, the systemic barriers that were noted above by the participants who acted as informal caregivers highlight that there these barriers to seeking any form of help are embedded within their culture and are personal in terms of resources to finance round-the-clock caregiver assistance.

This is consistent with Parker et al.'s (2020) study suggesting that the fear and shame around the diagnosis led to fear of being pitied or judged by family members. Further perpetuating the stigma around the disorder.

Moreso, the normalisation of the symptoms as being a ‘normal part of ageing’ was also noted as a form of denial (Parker et al., 2020). Leading to misunderstanding the disorder from a caregiver perspective, ultimately, affecting the treatment-seeking process. However, a unique and important barrier within the participants narratives was that of familial duty and cultural expectations. This was often emphasised in different participants’ narratives, despite the fact that it may have further marginalised the family, added strain onto the family system, and isolated the diagnosed relative from the community. It is worth noting that based on these findings, in addition to the global barriers, within a Hindu context – the barriers of care are intensified by familial duty and cultural expectations.

4.7 Family Support vs. Professional Services

According to Lim et al. (2012) the caregiving burden on family members who have a Dementia relative, is high. Which posits why support for the family is significant. Most participant narratives revealed that their relative diagnosed with Dementia received support from their families. However, participant six highlighted that along with the various changes that were implemented within the family system – in order to accommodate for the new family dynamics, there was also no initial support:

“Look, it was very difficult... I decided to build a house and accommodate him in there. So, we made everything kind of wheelchair-friendly, from the toilets, he could move around the whole house... My siblings were against it initially, but they didn’t have a choice”.

As a result, one can argue that due to the perceived response family members like participant six – would anticipate or receive, it became easier for family caregivers to resort to other forms of support to provide caregiving services such as domestic help.

Participant six also highlighted that establishing a collaborative family caregiving approach, reduced the pressure of one individual being responsible for everything (Zoladi et al., 2020).

Despite this, his narrative also reveals the hidden turmoil that caregiving has on family members who provide support:

“We tried to manage as a family, but it puts strain on everyone. My wife never complained, but I could see it took a toll.”

Lim et al. (2012) noted that due to the “presence of domestic help” family members would often not need to resort to professional services to seek help for their Dementia diagnosed relative (p. 1556).

Participant eight demonstrated that despite part of the cultural practice in Indian communities being, to take care of one’s relative, there was a need to employ another domestic helper to assist primarily with caregiving as opposed to seeking out professional caregiving services:

“We had to hire a second helper because our current helper has a close relationship with my brother”.

This further supports the discussion above on the caregiving expectation within Hindu families, noting that despite how difficult it may be to provide care, seeking out professional services is frowned upon. This is due to the embedded culture of collectivistic values that prioritise the family of the autonomous individual.

4.8 Individualistic Beliefs

In cultures that are more individualistic, the focus is on the individual (Grossman & Santos, 2016). In individualistic families or communities, the need to rely on family members’ to provide family caregiving is minimal. This is because providing caregiving is considered a process, whereby, professional or formal services are sought after due to the significance of attempting to establish a sense of autonomy for the diagnosed individual and the independence of family members once reaching adulthood (Pyke & Bengston, 1996).

The traits within individualistic cultures in terms of independence, autonomy, and relying on oneself are reflected in participant five's narrative who highlights that if he had the power or control to make a decision, he would. However, his narrative suggests that he had to accept the choice to provide caregiving for his diagnosed relative – instead of seeking out professional services:

“If I had my way, Mom would have been in a retirement home a long time ago... engaging in activities which I think might have slowed the progression”.

This further highlights that the participant considered seeking out retirement residential services to prolong his relative's life, instead of intending feeling duty-bound to care for his parent at home. Further supporting this, participant five noted:

“We end up thinking we're doing the best, but we actually isolate them a lot”.

This section signifies that within the South African Hindu context, it is rare to find individualistic beliefs – especially in relation to caregiving. This is because there is a strong sense of filial piety as well as informing one's identity around caregiving – as something that is tied to religious beliefs.

4.9 Collectivistic Beliefs

In cultures that are collectivistic, the focus is orientated more towards the community (Pyke & Bengston, 1996). Participant eight described an element of this collectivistic view by sharing how care is shared process, and not something that is done individualistically:

“Family helps when they can, but most of the burden falls on one or two people.”

Further demonstration, that it is a duty and sacrifice to be made in order to enhance the well-being of both the patient and the caregiver.

4.9.1 Familial Duty and Sacrifice

In line with this, the need to care also suggests that the family member who intends to provide caregiving is attempting to strengthen their family bond with their relative, but more importantly, to avoid allowing the diagnosed relative to feel isolated, unwanted, uncared for, unloved, or discarded by their family (Pyke & Bengston, 1996).

Most of the participants' narratives revealed that their process to provide direct caregiving was experienced as an oscillation between: 'unconditional love and care' towards family members as well as to provide the diagnosed relative with a sense of belonging and acceptance. Instead of potentially running the risk of making the diagnosed relative feel as if they are being rejected (Pyke & Bengston, 1996). This was seen in participant eight's narrative:

"My two boys were also leaning towards, 'this is family and let's do this for family'".

Supporting this, participant two demonstrated how this filial piety is transferred over from one generation to another (Wu et al., 2024):

"At night we used to take turns to watch her because she would get disorientated and walk around. It became a family effort."

Further highlighting that the process of family caregiving is normalised within Hindu families, even at young ages. In addition to this, it is also significant to note that the collectivistic understanding of caregiving as highlighted above is 'an act of duty' that is passed down from one generation to another.

In line with this, another trait of collectivistic beliefs is that of being 'cooperative'. This is seen in participant two's narrative, who reports that there was a sense of shared responsibility as well as a form of group collaboration within her family to provide caregiving for their diagnosed relative:

“My children were absolutely amazing... We had to put on a diaper for her, change her diaper several times, and bath her”.

Similarly, participant five described the manner within which she was brought up, based upon the belief and idea that putting your elders first is essential to being able to care for them.

“We have this tendency to want to care because that’s what’s instilled in us growing up, that you always put your parents first”

In contrast to the values of individualistic belief systems, the above narrative also highlights the importance of establishing a sense of sticking together as a family and making sacrifices together as a unit in terms of family cohesion in order to reduce or avoid any potential strain that may occur, despite the challenges, in comparison to if the caregiving process was taken on solely by one individual.

4.9.2 Sensitivity Towards Their Relative

Despite the strong collectivistic beliefs that were identified within the participants’ narratives, it is worthy to note that an element of maintaining a collectivistic way of being – is to be sensitive and responsive to the presence and needs of the diagnosed relative, despite any challenges. Participant four, described an element of how she intended to remain sensitive to her diagnosed relative’s needs and ways of being without placing any prejudice or form of patronising or outcasting her relative:

“She was quite happy sharing the task with me... She would sit and do the Havan (prayer) offerings into the fire”.

In line with being sensitive, Shatnawi, Steiner-Lim, and Karamacoska (2023) reported that being sensitive towards a Dementia diagnosed individual, constitutes what is known as a “Dementia-friendly community” (Shatnawi et al., 2003, p. 2025). As cited by Craig et al. (2024) “the idea of a Dementia-friendly community focuses on the lived experiences” of

individuals who are diagnosed with Dementia and their caregivers (p. 2). The aim of these communities is to address the needs of those diagnosed and those providing caregiving. In agreement with this, Mitchell et al. (2004) shared that these communities also promote community engagement. In a study conducted by Craig et al. (2024) the focus on Dementia-friendly communities yielded two positive outcomes for those part of these communities. Firstly, members part of these communities felt a sense of belonging and those who provided caregiving, felt supported (Craig et al., 2024).

According to Craig et al. (2024) most individuals who are diagnosed with Dementia live in communities. The culture and structure of a community is seen as a factor that contributes to how Dementia is understood. As noted by participant four who noted her relative's ability to remain connected to what she had always known:

“Whenever she walked into the house, the first thing she used to do was walk towards that Ganesha that I have in the front and offer her a prayer”.

Symbolising what Shatnawi et al. (2023) report with regards to the idea of continuing to establish communities, whereby, there is an element of what the patient has always known, such as religious practices, in order to encourage a sense of comfort towards the diagnosed relative – even in communities where collectivism is a significant way of being. Furthermore, this also highlights what the Alzheimer's Disease International (2017) stipulated, that if a Dementia-friendly community is established it instils a sense of autonomy in the diagnosed individual and empowers their caregivers, reducing the negative impact experienced on both sides. This being surrounded by the familiar also highlights that despite the 'duty to care' that is common within Hindu families, as was discussed above there are appropriate ways to instil this form of care, without revoking the rights of the diagnosed individual.

The narratives that were presented within the study, highlight the prevalence of collectivistic beliefs that are more predominant within Hindu families as opposed to individualistic beliefs. Further noting that the elements of upholding a collectivistic belief system, on behalf of the family caregivers, involves adopting certain traits or attitudes which were noted in participant narratives such as: making sacrifices, reinforcing a sense of togetherness, and being sensitive towards the other to instil a sense of comfort for the diagnosed relative.

4.10 Retrogenesis

According to Reisberg et al. (2002) the concept of Retrogenesis, is defined as “the process by which degenerative mechanisms reverse the order of acquisition in normal development” (p. 202). In other words, individuals who are diagnosed with Dementia of Alzheimer’s type lose specific skills, which are basic to their daily functioning, in the opposite order as they have learnt them – as infants/children.

There are various developmental abilities and/or skills that are lost in a Dementia of Alzheimer’s type relative. The narratives obtained from participants highlighted the regression was across multiple levels.

If one had to consider Swiss developmental psychologist Jean Piaget’s cognitive developmental stages in relation to children, it would be understood as follows:

1. The Sensorimotor Stage (Birth – Two Years Old): Infants learn through developing their senses and through movement. During this stage, a child learns object permanence, which refers to the ability to know that an object exists even when it is out of sight.
2. The Pre-operational Stage (Two – Seven Years Old): Children start to establish vocabulary and are able to make sense of symbols.

3. The Concrete Operational Stage (Seven – 11 Years Old): The ability to think concretely about situations starts to develop. In other words, the ability to categorise items into groups, reversing actions mentally, and the ability to think about multiple things at once.
4. The Formal Operational Stage (11 Years – Older): The ability to start thinking abstractly and use one's logic to solve problems.

However, in relation to individual's diagnosed with Dementia of Alzheimer's type, the individual starts to lose these abilities in a reverse order. For example:

1. The Formal Operational Stage: This is the equivalent of *early-stage* Dementia, whereby the individual has difficulty with remembering events that have occurred recently, but remembers things that occurred in the past.
2. The Concrete Operational Stage: This is the equivalent of the *moderate* stage of Dementia. The individual is unable to complete certain tasks like bathing or dressing themselves, on their own.
3. The Pre-operational Stage: This is the equivalent of the *moderately to severe* stage of Dementia. In this stage, the individual finds it difficult to communicate or requires significant assistance with their personal care.
4. The Sensorimotor Stage: This is the equivalent of having *severe* Dementia. At this stage, the individual has no verbal abilities, may struggle to walk, sit up on their own, and requires full time care.

By considering the above, it appeared that in participant one's narrative, a sense of dependency and likely separation anxiety was highlighted:

"If I'm not going to be in the house, I had to slowly prepare her because she'd become very anxious if I'm not there".

This further constitutes a sense of the relative with Dementia having regressed and being attached to their caregiver, often seen in infants, not in adults. This appears to be in line with moderate stages of Dementia onward.

Similarly, participant two shared that her relative would throw ‘tantrums’ which appears to reflect what Piaget would consider as an early developmental stage in children:

“She would throw tantrums when she didn’t want to eat or bath, just like a child. You’d have to calm her down and distract her.”

Whereas, participant six highlighted the regression of one’s ability to do things for themselves on a daily basis:

“ She forgets to take her medication. Then she takes her medication and then she takes it again and then again because she forgot what she did”.

Additionally, participant six also noted the regression of eating and how it regressed to the early maternal forms of feeding:

“She wanted to eat with her hands, refused to use a spoon, and wanted me to feed her. It reminded me of my children when they were toddlers”.

Table 4.3 below outlines Reisberg’s (2002) stages of retrogenesis in patients with Alzheimer’s disease. This framework illustrates the progressive decline in cognitive and functional abilities, showing how individuals lose skills in the reverse order in which they were acquired. Presenting these stages provides context for understanding the participants’ caregiving experiences, as the progression of the disorder directly influences the level of support required from family caregivers.

Table 4.3 Reisberg's different stages of retrogenesis in Alzheimer's patients (Reisberg, 2002, p. 204).

Normal development (approximate total duration: 20 years)	Approximate age		Approximate duration in development	Acquired abilities	Lost abilities	Alzheimer stage	Approximate duration in AD	Developmental age of patient	Alzheimer's degeneration (approximate total duration: 20 years)
	Adolescence	13 – 19 yrs	7 yrs	hold a job	hold a job	3 (incipient)	7 yrs	19 – 13 yrs (adolescence)	
	Late childhood	8 – 12 yrs	5 yrs	handle simple finances	handle simple finances	4 (mild)	2 yrs	12 – 8 yrs (late childhood)	
	Middle childhood	5 – 7 yrs	2½ yrs	select proper clothing	select proper clothing	5 (moderate)	1½ yrs	7 – 5 yrs (middle childhood)	
	Early childhood	5 yrs	4 yrs	put on clothes unaided shower unaided toilet unaided control urine control bowels	put on clothes unaided shower unaided toilet unaided control urine control bowels	6a (moderately severe) b c d e	2½ yrs	5 – 2 yrs (early childhood)	
		4 yrs 4 yrs 3 – 4½ yrs 2 – 3 yrs							
Infancy	15 mo	1½ yrs	speak 5 – 6 words speak 1 word walk sit up smile hold up head	speak 5 – 6 words speak 1 word walk sit up smile hold up head	7a (severe) b c d e f	7 yrs	15 mo – birth (infancy)		
	1 yr 1 yr 6 – 10 mo 2 – 4 mo 1 – 3 mo								

In line with what Reisberg et al. (2002) have identified as stage four, whereby there is an element of forgetting how to do certain things without having another individual present – to provide supervision.

Furthermore, the loss of the ability to care for oneself as seen in the more moderate to severe stage of Dementia is also demonstrated in participant six's narrative, who describes the regression of feeding abilities:

"He'll sip it with a straw... He'll have his whiskey in a tall glass with a straw".

Taking into account that most of the participants' narratives revealed retrogenesis, it is important to note that in Dementia of Alzheimer's disorder – there is a loss in the acquisition of one's developmental skills.

In conclusion, linking back to the literature review, the concept of retrogenesis does not explicitly derive from Piaget's theory of cognitive development (Blake & Pope, 2008). The findings noted in the retrogenesis and sensitivity sub-themes above, demonstrate that there is a conceptual alignment between the two frameworks. However, when analysing participants responses, it is evident that individuals diagnosed with Dementia of Alzheimer's type exhibit a progressive loss of their cognitive and functional abilities in a sequential and reverse order, that appears to mirror Piaget's theory of cognitive development (Blake & Pope, 2008; Reisberg et al., 2002). Moreover, highlighting the burden of care that is placed onto the caregiver as one that may later result in caregiver burnout.

4.11 Caregiver Burnout

In line with the above example of the relative who required a straw in order to drink something, it was also noted that retrogenesis also has an impact on the caregiver. As noted by participant six:

"He'd mess (encopresis) by mistake and forget. He wore nappies, but it was still a draining process. I did that for two months and then I couldn't anymore."

As supported by Stephanou (2023) who suggests that the responsibilities that are placed onto caregivers, often lead to severe exhaustion – which later on affects the caregivers mental and physical well-being. This is also linked to the tendency that the caregiver intends to place their relatives needs first, before their own (Stephanou, 2023).

Supporting this, participant eight shared the feelings of hopelessness and emotional depletion that was experienced due to her caregiving experience within the context of her family of procreation:

"I do have those emotions go through me because I've had to change the course of my life. It's impacted my husband, my son, and I... So, yes, it's impacted my family life. ... I do feel

alone because I question myself. 'Is this something I put onto my shoulders or was it inevitable?' ... There's this whiff of resentment, sadness. Why did I choose this life? Can it just be done already?"

Whereas participant two shared the physical strain of caregiving that later leads to caregiver burnout as follows:

"During the night, she was screaming, she was disorientated... She was also in diapers... I had to help her physically get dressed, and also feed her. We had to change her diaper several times during the night... You have to deal with somebody's mental health when they're physically not strong."

She also further stated later on in the interview, that the burnout was beyond a physical experience and rather one that was felt more emotionally:

"At that time, it was extremely difficult. ... Each day her physical body became weaker. You're putting diapers on someone who used to be independent — and she's screaming at you. It wears you down emotionally."

Furthermore, participant seven, despite the caregiver burnout described the conflict that arised when solutions to reduce the burnout were brought up:

"My sister said... if she's going to be this stubborn, then we're going to have to tell her that if she goes to Durban, she has to go to a care facility... My dad said very clearly, 'I don't want her in a care facility. A Hindu family doesn't do that and we will look after her.' ... It was going to be an expensive exercise... but, we will find whatever means we have to."

It is worth noting that caregiver burnout and the process of retrogenesis are two concepts that exist together. Whilst the developmental skills and abilities are often lost in Dementia of Alzheimer's type patients, so are their past memories. Instead, the gap made by lost or

checkered memories is then replaced with ‘false memories’ (Belli et al., 2020). This is known as confabulation (Belli et al., 2020).

4.12 Caregiver Tracking Symptoms

4.12.1 Confabulation

According to Belli et al. (2020) an early sign of Dementia of Alzheimer’s type is often the presence of confabulation which refers to an individual creating ‘false memories’ that are incongruous to their past. This is seen with participant two who appeared to be providing an alternative reality to her deceased sons:

“She had many sons... all her children had died except two daughters. But, she didn’t know her sons were dead. As far as she was concerned, her sons were alive. I couldn’t tell her they were dead, because in her mind, she lived for her sons.”

Similarly, participant four reported that her relative appeared to be recreating familiar memories from the past with what she believed was a recent memory:

“She used to say her mother was coming home soon... her mother had passed away over thirty years ago. She’d wait by the door and tell us not to cook because, ‘Ma is bringing food.’ We’d just let her say it because correcting her made her cry.”

It is worthy to note, that confabulation is not lying, but a determinant of the severe progression of the disorder (Belli et al., 2020).

Often individuals with Dementia displace their past memories as a result of not being able to make sense of the memory, in relation to the period of time within which the memory may have occurred. This is classified as spontaneous confabulation. Participant four demonstrates this type of confabulation witnessed from her relative, as she initially describes when she started noticing the symptoms of the disorder as follows:

“So Navratri, one of the prayers that she used to observe quite diligently was like, you know for the nine Saturdays. And with her, I used to take her to go and do shopping and for that prayer, you had to make like nine sets of offerings. And, then two separate ones, which meant 11. And then the one year when I took her shopping and she comes home and I see she only has seven. I told her, I said, ‘Mom, why do you only have seven? It’s supposed to be nine and two’. And then she says, ‘No, it’s seven. It’s seven. I have five and two and I’ve always been doing that’. So, she used to get very angry”.

Neuropsychiatric symptoms reported by participant four’s caregiver above such as agitation and anger are common symptoms that accompany patients diagnosed with Dementia (Cerejeira et al., 2012). Choudry et al. (2025) report that agitation is considered as “one of the most challenging behavioural symptoms associated with dementia” (p.1). This is often displayed in forms of verbal and physical outbursts (Choudry et al., 2025). In the same paper, it was noted that the presence of agitation can also worsen the patient’s condition which is why managing this symptom is crucial for the individual’s well-being as well as their and others’ safety.

Also corroborating what Belli et al. (2020) notes, the above is considered as a means to justify the memory, on behalf of the diagnosed, by having a strong conviction to defend himself/herself against the family caregiver.

Furthermore, it is interesting to note that participant six’s family member appears to avoid confronting the memory gap that is witnessed as he is attempts to make further sense of his relative’s symptoms:

“He’d look at my kids when they go and visit, and then he’ll forget their names. And, they know now, he forgot his thinking. It does come back after sometime. Sometimes it doesn’t comes back. He’ll change the subject and carry on”.

This also highlights that even for the caregiver, it is easier to avoid confronting the ‘false memory’ especially if one were to consider the collectivistic way of being, that is seen in Hindu families. This may be due to the fact that caregivers are afraid of perpetuating the stigma around the disorder or may feel the need to protect their relative, instead of highlighting their memory lapses or loss.

Despite the difficulty of witnessing a relative experience a cognitive decline, the presence of confabulation on behalf of the diagnosed individual, creating false memories is seen as an ‘appropriate’ symptom of Dementia – due to the fact that it is often seen as a defence mechanism. Shielding the family and the diagnosed individual from the reality of the neurodegenerative decline that appears to unfold.

In conclusion, this section highlighted the intersectionality between Hinduism and Dementia within a South African context. Participants’ narratives revealed that stigma is present within their daily experiences, in relation to their diagnosed relative. Furthermore, religious concepts such as karma and reincarnation were used interchangeably as forms of coping for caregivers to make sense of their diagnosed relatives diagnoses. At the core of participants’ narratives, it appeared that role reversal remained a significant barrier in the caregiving process as it involved processes of parentification as well as adjusting one’s lifestyle to various changes.

Other systemic barriers were identified such as symptoms being normalised, financial constraints, limited access to knowledge, and cultural expectations of care within the Hindu community.

The findings from this chapter will inform recommendations for future studies and the limitations of the current study will also be outlined in the next chapter, which can hopefully inform further research.

Chapter 5: Conclusion

The following chapter will provide an overall discussion on the findings of the study. Limitations identified in the study will be also mentioned, with recommendations provided for future research directions.

5.1. Overall Research Findings

Considering the prevalence of Dementia across the world, Nichols (2022) reported that there is an expected increase from 57.4 million cases to 152.8 million cases in 2025. Similarly, Combrinck et al. (2017) conducted a research study in South Africa and reported that according to the WHO an approximate of over 187 000 people, that are over the age of 60 years old, living in South Africa, would be living with Dementia in 2017. This was reported to increase to 250 000 people diagnosed by the year 2030 (Combrinck et al., 2017). Additionally, a more recent study conducted in South Africa revealed that Dementia is currently being considered as being part of the higher causes of mortality (Mahomed & Pretorius, 2022). Despite this, as risk for the neurodegenerative disorder increases so does the demand for caregiving services.

Taking this into account, Dementia is considered to be one of the leading neurodegenerative disorders causing disability as well as the seventh leading cause of death (WHO 2025).

Dementia poses a financial and economic burden on countries, which varies according to the resources available in that country (Garcia-Martin et al., 2023). Despite this, the neurodegenerative disorder is said to also involve a significant caregiving burden on those who provide caregiving for their diagnosed relative (Garcia-Martin et al., 2023).

Due to how different cultures perceive care and the manner within which it is provided, this appears to determine how care is decided upon (Garcia-Martin et al., 2023). In some cultures, such as the Western way of being, care is often provided by admitting a family member to a caregiving facility. Whereas, within the Hindu culture – or a broader Indian culture, the

provision of care is expected to be provided for by the diagnosed individual's family members (Bindlish et al., 2025). This form of care is informal and often seen as one's duty in line with the collectivistic values outlined in the current study. Zwingmann et al. (2020) stipulated that family caregiving makes up the largest fraction for caregiving. Parker et al. (2022) reported that due to this informal caregiving provided by family members is seen as a "chronic stressor in that it can create physical and psychological strain over prolonged periods of time" (p.2). This is consistent with what Jansson et al. (2001) reported, whereby, the care provided by non-Dementia caregivers is not as strenuous as the care provided by Dementia caregivers.

The current study was undertaken within a South African context, in the province of Gauteng in the large cities of Johannesburg and Pretoria. The population the study aimed to obtain data from were required to be Hindu Indians in terms of religious and ethnic identities. The aim of the study was to fill in the gap for literature available regarding how Hindu families, living with and informally caring for their relative who has and/or been diagnosed with Dementia of Alzheimer's Type further understand and perceive the neurodegenerative disorder from a caregiving perspective. The study sought to answer the following research question: What are the experiences of Hindu families caring for and living with a Dementia of Alzheimer's type patient?

The findings of the study show the various emotional, physical, financial and psychological challenges of Dementia, that are experienced by the diagnosed individual's family caregivers. The study further explored whether the religious views embedded within Hinduism had any influence over how the neurodegenerative disorder is perceived and treated by those providing informal caregiving.

The participants in the study shared their caregiving experiences, highlighting that they all had to make lifestyle changes in order to accommodate their diagnosed relative. Their responses also revealed how in addition to lifestyle changes, managing medication, feeding, bathing, assisting with using the toilet, adjusting to their relatives' diagnosis and containing their relatives emotionally were elements of their caregiving.

Kalavar et al. (2020) reported that as an individual ages, their risk of being diagnosed with Dementia increases too. This is because aging is also associated with multiple co-morbidities such as a decreased functioning in the cardiovascular system; having physical impairments; and mental difficulties that lead to difficulties in daily functioning. Each caregiver, held differing beliefs, based on how they were raised and taught the various values within their religious realm in relation to caring for someone else. A common shared experience expressed by some of the caregivers, was being able to shift between assisting their diagnosed relative with their activities of daily living and being able to adapt themselves as caregivers to the personality changes that caused significant challenges for the diagnosed individual.

Whilst other caregivers described their experience as part of their 'karma'. This was supported by the notion that caregiving was part of their required duties, assigned to them by their faith. The study highlights why understanding these cultural elements of how Dementia is understood, specifically from a clinical perspective, is pivotal to also understand the process of how treatment is sought after and adhered to by said caregivers.

It is worth noting that as caregivers reported a progression in their relatives' diagnoses, their roles and responsibilities also increased significantly (Liu et al., 2020). Further demonstrating that, the neurodegenerative disorder not only affects the diagnosed individual, but it also has a severe impact on the family. All participants shared that they had to make sacrifices in

terms of their increased availability to their relative, and their commitment to the notion of family obligation to care.

Whilst attempting to accommodate for their diagnosed relative, emotionally the weight of caregiving for a Dementia diagnosed individual is perceived as an emotionally straining process. This is because it is also a process of grief. Mahomed and Pretorius (2022) reported that Dementia is a disorder that appears to not be spoken about. This comes as a result of how the disorder is understood. Apart from the scientific facts of the disorder, there is a reality of loss that illuminates how the disorder is perceived. Mahomed and Pretorius (2022) highlight how a dual process of dying is experienced by the caregivers. Caregivers mourn the loss of who their relative one was and further mourning the relative, after they have passed on.

In addition to the above, the manner within which the disorder is understood also demonstrates how the access and availability of knowledge regarding the disorder, is minimal. Not because there is minimal scientific information regarding the disorder but moreso, as a result of individuals not having enough information to formulate their understanding of the disorder. This has a direct impact on how supportive and adherent the family members are – as not having enough information to understand the disorder, leads to defaulting on treatment and possibly not wanting to adhere to the medical treatment. Some caregivers in the current study attributed Dementia as a normal part of ageing, whilst some also revealed that they believed it was destined for the relative by a greater power; this is similar to the findings in Mahomed and Pretorius (2022).

This line of thinking also suggests that the caregiver's belief system and knowledge prior to providing caregiving, has a direct influence on the caregiver's intentions as well as their attitude. Supporting this, Dai et al. (2020) stipulated that if a caregiver has a higher level of knowledge pertaining to Dementia, they are better prepared and able to caregive for their

relative. This is because an unconscious process of person-centered care is implemented as opposed to relying on the notion that ‘Dementia is part of the aging process’. Whilst caregiving is considered as a second-hand nature, it does require a form of training or exposure to knowledge to aid the caregiving process (Dai et al., 2020).

Bearing the above in mind, it appeared that at times, caregivers in the current study would attempt to normalise their relative’s symptoms as a means of interpreting the symptoms through a religious or spiritual framework. Hossain et al. (2018) described how the awareness and understanding of Dementia amongst individuals within Indian communities is poor. This is because the symptoms of Dementia are either considered to be a normal part of ageing but more so seen as a result of being possessed or being punished by God (Hossain et al., 2018). This also reinforces that spirituality does play a role in how the disorder is understood.

In line with this, despite understanding of the disorder, family caregivers run the risk of being marginalised or isolated from their wider external system and larger networks of support and resources. This comes as a result of not wanting to speak openly about the disorder. As a result of this, a sense of shame is then internalised by both the caregiver and the diagnosed relative (Dai et al., 2020).

Furthermore, the study highlighted how dominant barriers would also affect the provision of and access to healthcare services. A common theme here, was that cultural expectations were perceived as barriers that marginalise caregivers from seeking professional care and maintaining follow-up treatment appointments. It appeared that caregivers held their filial piety to the highest regard, further highlighting that despite how significant or progressive the disorder became – seeking any form of professional care or treatment, was viewed as being inappropriate and risky to one’s own destiny in their next life.

Due to the significant belief that the participants held and with regard to all participants being part of a collectivistic culture – by considering their filial piety, it is worth noting that participants reported that they choose to caregive, over and above the religious duty to, as opposed to seeking out specialised care (Bindlish et al., 2025). This also highlights how seeking help has a certain shame attached to it. Some of the participants revealed the internalised shame that they adopted because of ‘what will others say’ or the isolation that they experienced as well. Moreso, not only was the caregiving considered as a filial piety, but it was also seen as being a form of taking care of one’s own karma too.

Another important finding in the study revealed the difficulty of having roles reversed between caregivers and their relatives. The shift in roles being reversed between a caregiver and their relative, highlighted that the process is emotional and multifaceted in terms of adjustment. This is because participants reported that they were required to take on certain responsibilities that were traditionally associated with the role of their diagnosed relative prior to being diagnosed. Most of the participants’ narratives described the process as a dual loss, as not only are their relationships lost but their diagnosed relatives’ identity and ability to function are elements that are also lost.

Caregivers often described their disbelief in how exponential their relative’s decline in cognitive functioning was, further debilitating their relative to a point of child-like regression. This regression of the diagnosed relative occurs alongside a process of anticipatory grief by the family. The Alzheimer’s Association (n.d.) shared how the loss of a family member, not physically, but psychologically – has a profound impact on family members. This was commonly highlighted within all participants’ narratives, as most participants shared their experiences with their parents being diagnosed with Dementia. Some participants described the difficulty of no longer being able to relate or rely on their parent but rather having to relate to their parent as their child. The reversal of roles led to a loss of participants having an

internal sense of mastery and instead, being conflicted and doubtful of their abilities to care for their parent.

The significant progression of how the Dementia was described, mirrors what Reisberg et al. (2002) coined as retrogenesis. This refers to a process whereby an individual loses certain abilities, in the opposite order within which these abilities were acquired. This theme was revealed within the participants' narratives with regards to diagnosed relatives requiring full support with activities such as going to the bathroom, having a shower, and eating (Reisberg et al., 2002). Coupled with confabulation, which refers to false memories often exhibited by patients with Korsakoff Syndrome or Dementia of Alzheimer's type (Kopelman, 1987).

Caregiver burnout is considered a common experience reported amongst caregivers, due to their stressful experience (Awwaliyyah et al., 2024). Despite this, the syndrome itself is still characterised as a mental health problem that is perceived as taboo. As a result, it is not discussed amongst caregivers.

Due to the burnout that was inadvertently reported by participants, it appeared that confronting or disagreeing with their relatives' false memories – remained a task that was often avoided. The thread common to these narratives suggested that participants intended to protect their relative's dignity (Straats et al., 2024) while also decreasing the risk of their diagnosed relatives from being further marginalised within society.

Together with the caregiver burnout reported, it appeared that participants would also rely on their cultural and religious belief systems as a means of coping, but also as a way of providing caregiving. Religious coping is understood as a form of seeking religious support to alleviate stress. It is considered as “coping that is believed to be related to psychological adjustment to the extent to which it solves the problem at hand or alleviates the distress it

generates” (Park et al., 2017). Readjusting to their new ‘normal’ required relying on a belief system that would alleviate their emotional difficulties and instead provide a form of structure – in terms of how family caregivers can ‘provide care’.

In line with participants beliefs around karma, which refers to the cause and effect of one’s behaviour it was apparent that reincarnation was also pivotal in terms of how some participants understood their relatives’ diagnosis (Bhatia, 2014). Reincarnation refers to the transition of one’s soul from one lifetime to another, “based on past actions” (Bhatia, 2014, p. 90). Without karma, reincarnation would not exist and would impede the individual’s ability to achieve their moksha. Moksha refers to the liberation that an individual seeks in each lifetime, to break free from the karmic cycle (Bhatia, 2014).

Significant to this understanding, some participants also held the belief that their relative’s diagnosis was as a result of their karma. Some of the participants revealed that their relative’s diagnosis was part of their reincarnation process. These religious and spiritual mechanisms appeared to also function as coping mechanisms for some participants.

Present within the narratives, were barriers to care. Consistent in a study conducted by Jacobs et al. (2023) focusing on Dementia in South Africa. Common to the study, was barriers identified to accessing care that is prevalent in South Africa. Participants described their encounter with inadequate services, such as a shortage of trained caregiving nurses that are affordable and specialist doctors, aimed to assist them with understanding their Dementia of Alzheimer’s type relative. Whilst other participants revealed that the adjustments made, involved financial decisions which caused financial strain and the full reliance on another informal caregiver to provide caregiving for their relative (Jacobs et al., 2023). Whilst these appeared to be the two most prevalent factors in terms of accessing care, they also highlight the need for more trained professionals who are equipped to better understand and care for an

individual diagnosed with Dementia. This would decrease family caregivers from providing care that is inconsistent or inefficient.

Additionally, it was evident that participants required practical as well as emotional support. Steiner et al. (2008) cited Dorsay and Vacca (1998) stating that “Caregivers, no matter what personality, need support and respite from care to be successful in their efforts” (p. 2).

Despite the collectivistic beliefs regarding how caregiving is perceived, participants described that family support as well as religious communities such as the those belonging to the same religious group or temple are significant for caregiving to be effective.

Moreso, one participant shared that in collectivistic cultures, apart from psychoeducation to reduce the misunderstanding of Dementia. Religious leaders should use their positioning within the religious institute to increase the psychoeducation of disorders.

The systemic understanding of participants narratives closely aligns with Urie Bronfenbrenner’s Ecological Systems Theory, which situates the Dementia diagnosed individual within multiple, interacting layers of influence. Highlighting the family, who in this study provide informal caregiving, representative of a central microsystem. Both theoretical frameworks emphasise that the diagnosed individual’s functioning and the informal caregivers’ experiences of Dementia cannot be understood in isolation, but rather as embedded within broader cultural and Hinduist belief systems.

5.2 Limitations of the study

The study provided valuable insights into how individuals within a Hinduist group, provide informal caregiving for their diagnosed relative. Bearing this in mind, limitations of the study have been identified which provide insight into how the findings of the study are interpreted as well as how future research studies should be conducted.

Due to the nature of the study being a qualitative study, an in-depth exploration of the study was undertaken. As a result, one of the limitations of the study was that the study sample size was small. The sample size was eight participants who reside in Gauteng. This is not inclusive of the entire Hindu population nor their experiences providing informal caregiving for their relative diagnosed with Dementia of Alzheimer's type within the Republic of South Africa. Considering this, the sample size is an indication of the possible findings – if the sample size were larger and across provinces.

Secondly, another limitation of the study was that the study had a religious niche. The study was designed to obtain data from individuals who follow a Hindu belief system. Although this was implemented to ensure a homogenous cultural sample, the sample was not diverse enough to represent family caregivers within the larger Indian context, nor is it representative of all family caregivers in Gauteng.

Additionally, due to the design of the data collection method being semi-structured interviews – the data collected may have been limited or constrained due to the sensitivity of the topic. Whilst on the other hand, the nature of the research topic also suggests the emotionally-charged experiences of caregivers. This may have also impacted how participants' responded in their interviews. This is known as 'response bias or 'social desirability bias', whereby, individuals exert a certain influence over how they respond to certain questions, in order to provide responses that are favourable (Wetzel et al., 2016).

Contextually, while the study focuses on the South African Hindu community – concepts such as reincarnation, karma, and the filial piety are not all-encompassing to represent other religious phenomena that may often be used to make sense of disorders and other elements of life.

Common in qualitative research, is the researcher's positionality within the study. Despite the continuous reflective processes and journalling that was implemented by the researcher, the manner within how participants' narratives were interpreted within this study – may highlight an element of subjectivity.

The study provides a valuable insight into how Dementia is understood from a collectivistic and spiritually-orientated group of Hindu devotees within an urbanised context. This niche may provide a foundation for future research within a similar context to be conducted. As such, the city of Durban in the province of KwaZulu-Natal within South Africa may likely be a transferable context in a future study.

5.3 Future Recommendations

It is recommended that future research on the topic, should incorporate a larger sample size. This will ensure a broader representative sample of the religious group and will ensure accuracy of the data.

Furthermore, instead of focusing on one religious niche – different religious niches should be considered as participant inclusion criteria. This will ensure a broader and generalisable sample of how different religious groups within the Indian diaspora – experiences the provision of caregiving for their diagnosed relative.

Additionally, it is significant to note that future research into the topic requires a larger research endeavour be conducted. This will ensure that the topic is understood and explored more in depth.

In line with the demographical location of the study, it is recommended for the study to be conducted not only amongst one religious niche, but also across different religious groups –

in order to have a comparable set of research data to compare results to. This will aid in how religious understanding of a neurodegenerative disorder is applied.

It would be beneficial for clinicians who work with Dementia of Alzheimer's type patients to be further trained within the field – adopting a multicultural understanding of how the disorder is understood. This will aid in how clinicians make sense of Dementia patients from specific religious backgrounds and allow for a more integrative and holistic treatment approach, as opposed to only relying on psychoeducation from a biological or a neurological perspective.

Themes of role reversal, stigma, access to care, confabulation, and retrogenesis were found to shape the informal caregivers' experiences within the current study. While religious elements such as karma and reincarnation were meaning makers in the process of caregiving. The study further highlighted that barriers such as a lack of knowledge, financial strain, and lifestyle changes were factors that made the caregiving process challenging for caregivers. Despite these challenges, it appeared that the caregivers were able to provide caregiving by relying on their filial piety, their faith, and relying upon cultural beliefs.

Lastly, considering that there is a research gap on the topic of Dementia within South Africa, it is recommended for more studies to be conducted. This may reduce the cultural misunderstanding of the disorder and decrease the stigma regarding the diagnosis. This may also increase the efficiency for how the disorder is treated but more so, how it is further perceived.

The study emphasises that the act of providing informal caregiving is not only a task, but rather a human experience that is felt by caregivers on a profound level. The study can be seen as the foundation for future research that is cultural and focused on Dementia within a

Hindu context in South Africa or other developing countries. The study explored the experiences of family members who provide informal caregiving for their diagnosed relative and highlighted the intricacies of culture being intertwined with caregiving. The findings of the study demonstrated that the informal caregiving process is informed by a collectivistic belief system within a Hindu context.

In conclusion, the study contributes to the body of literature on Dementia within a South African Hindu context. Future studies should focus on exploring the caregiving experience by tracking the cultural elements of caregiving which may inform collectivistic views on caregiving in South Africa. This would in turn aid the policy making processes in terms of how caregiving is implemented within a collectivistic group and also improve how clinicians make sense of the neurodegenerative disorder from a cultural perspective.

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Appendix A

Ethics Clearance Certificate



College of Human Sciences_CREC

Date: 30/09/2024

Dear: Miss Liashna Pillay

NHREC Registration # : (Rec-240816-052)
Ref #: 3759
Name: Miss Liashna Pillay
Student #: 55901603

Decision: Ethics Referred back

Researcher: Miss Liashna Pillay

Masters in Clinical Psychology

Pretoria

55901603@mylife.unisa.ac.za 0799518691

Supervisor: Professor Christine Laidlaw christinelaidlaw@gmail.com

Exploring the Lived Experiences of South African Hindu Families – Living with and Caring for an Individual Diagnosed with Dementia of Alzheimer’s Type.

Qualification: Masters in Clinical Psychology

Thank you for the application for research ethics clearance by the College of Human Sciences_CREC for the above-mentioned research. The application was reviewed by College of Human Sciences_CREC on **30 September 2024**

The application is referred back for revisions and clarifications.

Please receive the comments from the reviewers. You may address these comments by amending the application.

Title	Comment
Is your research study, part of a catalytic niche area project, as identified by your college?	Request the supervisor to assist you and provide this information.
This proposal summary should be written in lay terms (non-technical, everyday language) and include:	The researcher should be careful with assumptions, not substantiated by literature.
Type of Application	Which secondary data will be utilized. Please include proof that permission for secondary data was obtained.
What procedures will the researcher	

Title	Comment
follow to obtain consent from the participant during this study?	A flyer to recruit participants is mentioned. The flyer could not be located. Please submit.
Please upload the informed consent form	The information letter should be written in simple language. It may be helpful to mention that they received this letter because they responded to the invitation on a flyer. The letter must be on official letterhead, and it should include the contact details for CREC.

1. The student should avoid anticipating the study's results and ensure a more neutral, exploratory tone throughout.

2. Clarify the statement that faith can "contribute to the lack of understanding" and consider whether faith might also offer unique insights, which is inconsistently addressed in the proposal.

3. The "problematic" aspects of faith should be handled with more nuance, avoiding bias.

4. Ensure consistency when describing Hinduism, as it is referred to both as a "philosophy" and an "ideology."

5. Provide more details on purposive sampling, gatekeeper contact, and how participants' religiosity will be considered.

6. The population size (50-100 participants) and the criteria for participants' mental and physical capacity to consent should be clarified.

7. Expand on how data will be securely stored and consider including participant validation in the analysis process.

8. The information sheet should mention the availability of psychological services for participant distress, and the rigor and reflexivity sections should be expanded.

9. A clear distinction needs to be made between primary and secondary data.

Please submit the revised **application within three months.**

Data collection activities, as indicated in the application documents, may not commence until final approval has been granted by the College of Human Sciences_CREC.

It is your responsibility to ensure that the proposed research adheres to the values and principles expressed in the UNISA Research Ethics Policy.

Please note:

If your re-submission does not adhere to the procedure set out above it will not be tabled for ethics review and will be returned to you within 48 hours.

Kind regards,



Prof Khatija Khan
Chair of College of Human Sciences_CREC
E-mail: khankb@unisa.ac.za

Appendix B

Letter to Dementia SA Organisation/Healthcare Workers



To Whom it may concern:

RE: Qualitative research study on exploring the experiences of South African Hindu families caring for an individual diagnosed with Dementia of the Alzheimer's type

My name is Liashna Pillay. I am currently enrolled in the Master of Clinical Psychology program offered at the University of South Africa. As part of my research component, I am currently compiling a research study that is qualitative in fulfilment of the research policies within the Psychology department at the University of South Africa. I am under the supervision of Professor. Christine Laidlaw, who is a qualified Clinical Psychologist and lecturer at the University of South Africa.

The aim of this research study is to understand the experiences of family members, who are Hindu, living with their relative who is diagnosed with Dementia of Alzheimer's type. In addition, the study further intends to explore how the philosophy of Hinduism affects the way Dementia from a general perspective and Dementia of Alzheimer's type is conceptualised, perceived and treated.

The study will be useful for practicing Psychologists as well as the broader Hindu community who may not understand Dementia of Alzheimer's type and as a result of this, a treatment gap as well as stigmatisation remain two of the highest concerns regarding the livelihoods of those diagnosed and those who are undiagnosed due to cultural beliefs.

I, hereby, kindly ask for you to grant me permission to access at least two of your caregivers who appear interested and consent to participate in this study.

The participants' narratives will remain anonymous, and all data obtained will be safeguarded, however the findings obtained will be utilised in the study after being carefully analysed. In addition, pseudonyms will be used to safeguard the identity of the participants.

The interview will be conducted either in person, closer to the participant or virtually on agreed upon platform. Participants will be briefed prior to participation regarding their right to withdraw, the importance of their consent as well as the notion of confidentiality. Participants will also be allowed to ask questions regarding any concerns they may have. The researcher understands the significance of protecting the participants from harm. Therefore, participants will be debriefed after participating in the interview as a means of containing any emotions or concerns that may have emerged during the

interview process. Participants who require further psychological support and debriefing will be referred to a designated independent Clinical Psychologist, whereby services offered are free of charge.

Once the study has been successfully conducted, it will be made available to the participant to keep. Please do not hesitate to contact me, in the event, that any questions or concerns arise. Your participation is dependent on your consent. Please kindly ensure that you consent to the study in order to participate, if you are unable to or change your mind to participate there are no legal or negative consequences.

Should you have concerns about the way in which the research has been conducted, you may contact Prof. Christine Laidlaw. You may also contact the research ethics chairperson of the College of the Human Sciences, Prof. Khatija Khan if you have any ethical concerns.

Thank you for taking the time to read this.

Sincere Greetings,

Liashna Pillay

Researcher: Liashna Pillay

Email Address: pillayliashna@gmail.com

Supervisor: Prof. Christine Laidlaw

Tel: +27 12 429 8294; Email Address: laidlc@unisa.ac.za

Chairperson of College of Human Sciences CREC: Prof. Khatija Khan

Tel: 012 429 6549; Email Address: khankb@unisa.ac.za



University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

Appendix C

Information Letter

Dear Potential Participant,



My name is Liashna Pillay. I am a Masters in Clinical Psychology Student Studying toward a Postgraduate Degree in the Faculty of Psychology at the University of South Africa.

You are receiving this information sheet after responding to my recruitment flyer. You are invited to participate in a study that involves my research on:

“Exploring the experiences of South African Hindu families caring for an individual diagnosed with Dementia of the Alzheimer’s type”

The prime purpose of this research is to establish the Following viz.:

1. What are the experiences of Hindu families living with a Dementia of Alzheimer’s type patient?

In addition, the following questions are secondary and aim to further explore the way that Dementia is perceived amongst Hindus:

2. How do Hindu families perceive and conceptualise Dementia?
3. How does Hinduism contribute to the stigmatisation of Dementia?
4. How does Hinduism affect the treatment and/or care of a relative with Dementia?

There are no risks to the participants of this interview. Therefore, participants will be debriefed after participating in the interview as a means of containing any emotions or concerns that may have emerged during the interview process. Participants who require further psychological support and debriefing will be referred to a designated independent Clinical Psychologist, whereby services offered are free of charge.

It is my expectation that the study will create an improved insight for the significance of understanding Dementia within a Hinduism society by means of reducing the stigma placed on those diagnosed by their Hindu family members and/or caregivers as well as healthcare workers.

Your participation in the study is voluntary. By participating in this research, you are granting the researcher permission to utilise your responses as part of the research methodology. You are at liberty to decline your participation in the study with no consequences should you decide to. Kindly note,

there is no monetary gain or reward for your participation in the study. Your anonymity will be maintained by the researcher and the Faculty of Psychology at the University of South Africa.

All data, both electronic and hard copy, will be securely stored during the study. On completion of the research, all data will be destroyed.

Should you have any questions or concerns about participating in the study, please contact me via email on pillayliashna@gmail.com

Should you have concerns about the way in which the research has been conducted, you may contact Prof. Christine Laidlaw. You may also contact the research ethics chairperson of the College of the Human Sciences, Prof. Khatija Khan if you have any ethical concerns.

Sincerest Greetings,

Liashna Pillay

Researcher: Liashna Pillay

Email Address: pillayliashna@gmail.com

Supervisor: Prof. Christine Laidlaw

Tel: +27 12 429 8294

Email Address: laidlc@unisa.ac.za

Chairperson of College of Human Sciences CREC: Prof. Khatija Khan

Tel: 012 429 6549

Email Address: khankb@unisa.ac.za



Appendix D

Informed Consent Form



I _____ (Name in full) have been informed about the study entitled *“Exploring the experiences of South African Hindu families caring for an individual diagnosed with Dementia of the Alzheimer’s type”*

I understand the purpose and procedures of the study

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

If I have any further questions/concerns or queries related to the study I understand that I may contact the researcher, Liashna Pillay, at (+27 79) 951 8691 or email pillayliashna@gmail.com.

Signature of Participant:

Supervisor: Prof. Christine Laidlaw

Tel: +27 12 429 8294 ; Email Address: laidlc@unisa.ac.za

Chairperson of College of Human Sciences CREC: Prof. Khatija Khan

Tel: 012 429 6549: Email Address: khankb@unisa.ac.za



Appendix E:

Semi-Structured Interview Questions

Question one

Being Hindu, what are the experiences you've had when finding out your family member has been diagnosed with Dementia?

Question two

Was receiving the diagnosis difficult to discuss with other family members (immediate and external family members)?

Prompts:

- A. If yes, why was it difficult?
- B. What other difficulties/challenges did you face when receiving the diagnosis for your relative?

Question three

Do you believe that Karma, Reincarnation, and Astrology are key factors in your family member's diagnosis with Dementia of Alzheimer's type? (Khosla et al., 2020; Laher & Padayachee, 2014)

Prompts:

- A. Tell me more.
- B. Did this impact your understanding or your interactions with your diagnosed family member? If yes, what was the impact on you?

Question four

Do you believe that the presence of a mental illness can be based on spiritual forces? (Mysorekar, 2006).

Prompts:

- A. If yes, what is your belief based on?

Question five

Do you feel that you had/have enough knowledge about Dementia? (Bala et al., 2015)

Prompts:

If not (A & B)

- A. How did you access information about the disorder and was it helpful?
- B. How did the lack of information impact your ability to care for your relative?

If participant did (C):

- C. How did having this knowledge assist you in understanding how to care for your relative?

Question six

When taking care of your family member diagnosed with Dementia of Alzheimer's type, did you receive any support from other family members? (Brodaty, 2009)

Prompts:

- A. If yes: What support did you receive and how did this help you?
- B. If no: Do you think you didn't receive any support because of your religion?

Question seven

Did you resort to pharmacological treatment for your family member? (Burns & Overshott, 2005)

Prompts:

- A. If yes: what treatments did you resort to? Do you think this was effective?
- B. If no: please elaborate further as to why you did not?

Question eight

Can you tell me about the Hindu beliefs you have regarding health? (Khosla et al., 2020)

Question nine

Were there any religious practices you had to consider in order to treat your diagnosed family member? (Khosla et al., 2020)

Prompts:

- A. Did you have to perform any rituals to protect you as the family member who takes care of the diagnosed family member?
- B. Did you contact the Pundit/Guru (priest) to open-book (meaning to open religious scriptures and/or texts) (Khosla et al., 2020)?

Question ten

Has taking care of your family member diagnosed with Dementia of Alzheimer's type been difficult for you?

Prompts:

- A. Identify a specific feeling/emotion (i.e., frustrating, lonely etc)
- B. Did/do you feel marginalised from the community? (Brijnath, 2014)
- C. What challenges did you experience?

Question eleven

Do you think that the way mental illness is conceptualised within Hinduism, as a stigma, can be reduced? (Corrigan & Watson, 2002)

Prompts:

- A. In what ways?
- B. If no, how do you understand mental illness?

Appendix F

Debriefing for Research Participants



Veren Gyapersad
Clinical Psychologist

 vgyapersad@gmail.com

 067 091 7038

www.verengyapersad.co.za

HPCSA Nr: PS0134430

Practice Nr: 0732400

B Soc Sci (UKZN) | BA Hons (UNISA) | MA Clin Psych (UNISA)

10 October 2023

RE: DEBRIEFING FOR RESEARCH PARTICIPANTS

Dear Miss Pillay,

This letter serves to confirm my availability to provide debriefing sessions to the participants of your research study. If required, participants are welcome to contact me for individual debriefing sessions if they experience any psychological distress as a result of the research interview and its processes.



Kind Regards,

Veren Gyapersad

Appendix G

DSM-5-TR Diagnostic Criteria for Major or Mild Neurocognitive Disorder due to Alzheimer's disease

Major or Mild Neurocognitive Disorder Due to Alzheimer's Disease

Diagnostic Criteria

- A. The criteria are met for major or mild neurocognitive disorder.
- B. There is insidious onset and gradual progression of impairment in one or more cognitive domains (for major neurocognitive disorder, at least two domains must be impaired).
- C. Criteria are met for either probable or possible Alzheimer's disease as follows:

For major neurocognitive disorder:

Probable Alzheimer's disease is diagnosed if either of the following is present; otherwise, **possible Alzheimer's disease** should be diagnosed.

1. Evidence of a causative Alzheimer's disease genetic mutation from family history or genetic testing.
2. All three of the following are present:
 - a. Clear evidence of decline in memory and learning and at least one other cognitive domain (based on detailed history or serial neuropsychological testing).
 - b. Steadily progressive, gradual decline in cognition, without extended plateaus.
 - c. No evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological, mental, or systemic disease or condition likely contributing to cognitive decline).

For mild neurocognitive disorder:

Probable Alzheimer's disease is diagnosed if there is evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history.

Possible Alzheimer's disease is diagnosed if there is no evidence of a causative Alzheimer's disease genetic mutation from either genetic testing or family history, and all three of the following are present:

1. Clear evidence of decline in memory and learning.
2. Steadily progressive, gradual decline in cognition, without extended plateaus.

3. No evidence of mixed etiology (i.e., absence of other neurodegenerative or cerebrovascular disease, or another neurological or systemic disease or condition likely contributing to cognitive decline).
- D. The disturbance is not better explained by cerebrovascular disease, another neurodegenerative disease, the effects of a substance, or another mental, neurological, or systemic disorder.

Coding note (see coding table on pp. 682–683):

For major neurocognitive disorder due to probable or possible Alzheimer's disease, with behavioral disturbance, code first **G30.9** Alzheimer's disease, followed by **F02.81**. For major neurocognitive disorder due to probable or possible Alzheimer's disease, without behavioral disturbance, code first **G30.9** Alzheimer's disease, followed by **F02.80**.

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Note: The severity specifiers "mild," "moderate," and "severe" cannot be coded for major neurocognitive disorder but should still be recorded.

For mild neurocognitive disorder due to Alzheimer's disease, code **G31.84**. (**Note:** Do *not* use the additional code for Alzheimer's disease. "With behavioral disturbance" and "without behavioral disturbance" cannot be coded but should still be recorded.)

For major or mild neurocognitive disorder due to Alzheimer's disease: Use additional code(s) to indicate clinically significant psychiatric symptoms due to Alzheimer's disease (e.g., **F06.2** psychotic disorder due to Alzheimer's disease, with delusions; **F06.32** depressive disorder due to Alzheimer's disease, with major depressive-like episode).