The South African Indian Hindu community's understandings and experiences of psychosocial disability

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DECLARATION

I, Sumaya Habib, declare that this research report is my original work. All sources used have been acknowledged in the report. This report is being submitted for the degree of Master of Arts in Clinical Psychology in the Faculty of Humanities, University of the Witwatersrand, Johannesburg. It has not been submitted previously for any degree or examination at any other University.

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ABSTRACT

Aim: Psychosocial disability is a layered concept engaged with from multiple perspectives, particularly in a culturally diverse country such as South Africa. Literature has discussed the prominent role that cultural understandings of psychosocial disability play in the treatment-seeking behaviours and accessibility to mental health care of individuals in different cultural communities. However, limited research has been dedicated to the cultural conceptualisations of psychosocial disability in the South African Indian Hindu community in contemporary South Africa and its practical implications. The aim of this study was to explore the South African Indian Hindu community's understanding and experiences of psychosocial disability.

Methods: This qualitative study used an explorative and interpretative framework to investigate a novel area of research and create shared meaning from subjective material. Data was collected through the use of semi-structured interviews where a sample of 6 participants were interviewed regarding their experiences with their family member with a psychosocial disability within the South African Hindu Indian community. Data were analysed using thematic analysis.

Findings: The findings identified three main themes: a 'layered understanding of psychosocial disability' which explored two main conceptualisations of psychosocial disability (cultural versus biomedical) across genders and generations. 'Secrecy and stigma' surrounding psychosocial disability, fueled by shame, negative cultural narratives and ignorance. And 'family experience' which encompassed the complex feelings associated with the emotional and physical care of family members.

Conclusion: Cultural understandings of psychosocial disability within the South African Indian Hindu community were experienced as integral in preserving the community's identity, and as having an impact on community members' engagement with care and support. However, cultural understandings were seen as absent from the South African mental health care system which was instead characterised as a biomedical space. The study reflected on the importance of a more integrative approach, an incorporation of both biomedical and cultural understandings, towards conceptualising and treating psychosocial disability in order to allow a more accessible and relevant form of mental health care for different cultural communities in South Africa.

Key words: community, cultural understandings, psychosocial disability, South African Indian Hindu

TABLE OF CONTENTS

List of tables

CHAPTER 1: INTRODUCTION AND RATIONALE

'Psychosocial disability' is an umbrella term used to describe a variety of mental health disorders (such as mood disorders, anxiety disorders, schizophrenia, and trauma-related disorders) that arise from psychological, social and/or biological dysfunction, that affect an individual's everyday functioning. (Kleintjes et al., 2013; Talatala et al., 2020). 'Psychosocial disability' not only refers to impairment, but also emphasises an individual's inability to participate equally in society. Research has focused on the prevalence of psychosocial disability globally and the financial, social andpolitical barriers to addressing the prevalence (Carbonell et al., 2020; Lund et al., 2012).Additionally, this research looks at the burden of care of psychosocial disability thatis then subsequently shifted from the State to individual families and communities, a very common scenario in low to middle income countries (LMICs) like South Africa (SA) (Engelbrecht & Kasiram, 2012).

Studies within the last decade, however, have shifted focus to exploring both barriers of, and interventions for, psychosocial disability from a more cultural perspective, as opposed to explorations from a strictly biological angle (Ally & Laher, 2008; Padayachee & Laher, 2014). The cultural struggles associated with psychosocial disability and the relevance of psychological interventions are a needed discussion, especially in a diverse country like SA, where there has been historical marginalisation of non-western communities in all aspects of life, including healthcare provision (Kleintjes et al., 2013; Talatala et al., 2020). The literature reveals intrinsic links between cultural understandings and experiences of psychosocial disability from various South African communities (Ally & Laher, 2008; Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). In the South African Indian Hindu community specifically, research has been conducted on the specific cultural beliefs linked topsychosocial disability, as well as stigma surrounding psychosocial disability linked to cultural beliefs. Furthermore, research has focused on experiences of psychosocial disability via individuals with psychosocial disability, their parent(s), their caregivers, spiritual guides, traditional healers and psychologists (Ally & Laher, 2008; Bhana & Bhana, 1984; Kathree & Petersen, 2012; Laher, 2014; Padayachee & Laher, 2014). However, this research only amounts to a handful of dated studies, revealing a large gap in knowledge surrounding a community that, although only makes up 2,7 percent of the South African population, is a unique and significant social group within contemporary SA (Statistics South Africa, 2024).

There is a high prevalence of psychosocial disorders globally, but specifically in

LMICs like SA (Carbonell et al., 2020; Lund et al., 2012). Literature has shown that cultural conceptualisations of psychosocial disability greatly influence the paths that individuals take in treatment and diagnosis of their disability (Ally & Laher, 2008; Padayachee & Laher,2014). In SA, a significant percentage of the population opt for more traditional routes of treatment (such as meeting with traditional healers, prayers, and rituals) (Laher, 2014). Theseforms of treatment do not necessarily engage with all features of the psychosocial disability (e.g., physical and emotional), and can prolong the individual's discomfort, thus worsening their condition (Yerriah et al., 2022). Incorporating cultural understandings into Western methods of diagnosis and treatment of psychosocial disability (increasing cultural competence), can help individuals from different cultural communities in SA feel more understood, respected, and see these integrated methods as representative and viable (Ally & Laher, 2008; Engelbrecht & Kasiram, 2012; Padayachee & Laher, 2014). Incorporating cultural understandings may also assists in increasing the treatment seeking behaviours of non-western communities, and narrowing the treatment gap (Lund et al., 2012; Padayachee & Laher, 2014; Schierenbeck et al., 2013).

The South African Indian Hindu community is a conservative community whose everyday interactions are guided by their investment in their religion and their strong family ties (Radhakrishnan, 2005). This community's experiences with psychosocial disability are greatly under-researched. Additionally, despite family connection and the family unit being such a prominent feature of the South African Indian Hindu community's cultural life, the handful of existing research on this community focuses on a wider community understanding of psychosocial disability, while the nuanced cultural experiences of individual family members with psychosocial disability remain unexplored. Therefore, current research focused on Hindu cultural ways of life, understandings, and cultural practices, with particular focus on family member lived experiences of psychosocial disability, can enable the provision of contemporary and relevant information about psychosocial disability in this community. Furthermore, current research can help to structure meaningful care and support to both the individual with the psychosocial disability, and the family and community which are often left to carry the burden of psychosocial disability care (Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014).

1.1 Research Aims

The study aimed to explore the South African Indian Hindu community's interaction with psychosocial disabilities, through everyday experiences with their family members that have

a psychosocial disability. In other words, how this specific community navigates through relates to and makes sense of the complex and socially layered concept of psychosocial disability. 'Psychosocial disability' here refers to dysfunction or impairment in a person's emotion, cognition or behaviour as a result of social, biological and/or psychological factors, that prevent an individual from functioning in society (Kleintjes et al., 2013; Talatala et al., 2020).This includes, but is not limited to, mood disorders, anxiety disorders, schizophrenia, and trauma-related disorders. Furthermore, the study aimed to explore what role cultural understandings play in this specific community's conceptualisations of mental illness and their resulting everyday experience of these illnesses.

This dissertation explores the South African Indian Hindu community's interaction with psychosocial disability through the following chapters: Chapter two reviews existing literature and identifies gaps in current research and approaches to the topic. In this chapter, these insights and gaps are used to inform the development of research questions regarding the South African Indian Hindu community's understanding of- and engagement with psychosocial disability. Chapter three, the methodology section, outlines the methods used in the undertaking of the study. This section includes a discussion of the research design, sample and sampling, research instruments, procedure, data analysis, ethical considerations and the principles of trustworthiness in qualitative research used in this study. Chapter four, the findings section, presents the collated data and introduces the prominent themes elicited from participants. Chapter five, the discussion section, contextualises the findings in relation to existing literature and reviews the practical implications of the findings. Chapter six, the last chapter, offers a conclusion, and reflects on the limitations of the study as well as provides recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

2.1. Prevalence of psychosocial disability

'Disability' is a term associated with 'impairment' (Grönvik, 2009; Talatala et al., 2020). This phrasing of disability as 'lesser' puts the responsibility on the individual with a disability to adapt to a way of life where their agency is limited and where it is impossible for them to meet the standard of what is considered 'normal' (Lang, 2009). This definition also negates the responsibility of the State to cater for the diverse needs and abilities of all individuals (Lang, 2009). Psychosocial disability forms part of this narrative. Psychosocial disability refers to an impairment in a person's emotion, cognition and/or behaviour as a result of social, biological and psychological factors, that prevent an individual from functioning in society (Kleintjes et al., 2013; Talatala et al., 2020). The term 'psychosocial disability' is often used interchangeably with the term 'mental illness' as both refer to an impairment in the mental functioning of an individual (Feldman & Crandall, 2007; Kleintjes et al., 2013; Talatala et al., 2020). While 'mental illness' is a more stagnant term associated with diagnosis, 'psychosocial disability' is a term that more accurately captures the experience of having a disorder (Feldman & Crandall, 2007; Kleintjes et al., 2013; Talatala et al., 2020). 'Psychosocial disability' not only refers to impairment, but also emphasises an individual's inability to participate equally in society as a result of internal and external factors and aligns more with the tone of the current study (Kleintjes et al., 2013; Talatala et al., 2020).

Psychosocial disability presents a pervasive problem in both high and LMICs, making up about 13% of the global disease burden and a third of the disease burden in SA (Carbonell et al., 2020; Lund et al., 2012). Even more concerning is that the mortality rate of individuals diagnosed with psychosocial disabilities is 2-3 times higher than the general population (Bonsu et al., 2020). Although psychosocial disability poses a great risk globally, there are still multiple barriers to receiving adequate care for it (Carbonell et al., 2020; Lund et al., 2012). The main barriers include: poorly developed mental healthcare policy, a focus on primary healthcare without the inclusion of mental healthcare, underfunding, high cost of treatments, a shortage of healthcare professionals, a lack of facilities, a lack of community services, and stigma (Carbonell et al., 2020)

2.2 South African barriers to mental healthcare

In SA, these barriers to mental healthcare are further exacerbated by limited resources, infrastructure, and different cultural conceptualisations of psychosocial disability (Talatala

et al., 2020). Over the years, South African policy makers have made continuous efforts to improve the mental healthcare system, attempting to address the huge disparity between individuals suffering from psychosocial disability and those being treated for it, otherwise known as the 'treatment gap' (Lund et al., 2012; Schierenbeck et al., 2013). These efforts have been pursued through several renewed commitments to providing adequate mental healthcare, local studies dedicated to the collection of data that can inform new and relevant policies regarding mentalhealthcare, setting up the *Mental Health Review Board* to protect the rights of individuals with psychosocial disabilities, and decentralising the healthcare system, thus making care more community based (Lund et al., 2012; Petersen & Lund, 2011; Schierenbeck et al., 2013). However, these attempts have been made more on paper than through significant structural changes and financial support (Hendricks et al., 2014). South Africans with psychosocial disabilities, particularly in low-income areas, continue to face barriers to much needed care (Lund et al., 2012).

The barriers to mental healthcare in SA are multifaceted, and often overlap, but can be broadly expressed as a *lack of access, resources,* and *knowledge* (Lund et al., 2012; Petersen & Lund, 2011; Schierenbeck et al., 2013; Talatala et al., 2020). *Lack of access* affects every step in the process of psychosocial disability management. Firstly, many individuals in low-income areas do not have access to information regarding psychosocial disabilities, their high prevalence, their treatability and the services available, meaning that individuals with psychosocial disabilities and their families do not seek assistance (Dockery et al., 2015; Schierenbeck et al., 2013). Secondly, individuals who are aware of their disability are often far away from available clinics, meaning that they must consider the expense of transport, time away from their job, and safety of travel (Schierenbeck et al., 2013). The SouthAfrican Police Service (SAPS) is provided as a public resource to transport individuals with psychosocial disabilities (such as those with psychosis or schizophrenia) from their homes to clinics. However, these parties are not trained in how to deal with these individuals appropriately which often leads to harsh treatment and often escalates the situation for themselves, the patient and their families, discouraging individuals from using this resource (Schierenbeck et al., 2013).

Lack of resources extends to a range of deficiencies within the mental healthcare system. To start with, there is a lack of mental healthcare facilities available (Schierenbeck et al., 2013). Inexisting facilities, primary and mental healthcare patients are treated in the same clinics resulting in lack of available beds, early discharge, inconsistent care and over-crowding. These conditions create a lack of privacy which disrupts the honest disclosure of

mental healthcare patients out of fear of being exposed or judged by other primary healthcare users. Honest disclosure forms an important part of psychosocial disability treatment and diagnosis,thus when mental healthcare users do not feel safe in these spaces, it is difficult forthem to access full and relevant care (Schierenbeck et al., 2013). The treatment of both primary and mental healthcare patients in the same facilities also leads to a lack of in-patient facilities andavailable medication (Petersen & Lund, 2011; Schierenbeck et al., 2013). In general, and in these facilities, there is a lack of trained mental healthcare professionals which then places the responsibility of diagnosis and treatment on unqualified professionals, like nurses, who may misdiagnose patients (Petersen & Lund, 2011; Schierenbeck et al., 2013).Additionally, individuals with psychosocial disabilities have reported being treated with distain and hostility by many staff in comparison to primary healthcare patients. This makespatients reluctant to return to these facilities (Lund et al., 2012; Schierenbeck et al., 2013).

The category of *lack of resources* emphasises the problems with the South African mental healthcare system. The integration of primary and mental healthcare in community clinics, with no additional resources, creates a constant state of stress and scarcity, as opposed to cost effectiveness and accessibility (Hendricks et al., 2014; Lund et al., 2012; Schrienbeck et al., 2013). Disorganisation, from the top down, and poor administration create a system where community-based programmes only have the capacity to focus on short-term treatments and medication compliance (Lund et al., 2012; Schierenbeck et al., 2013). Long-term treatment plans which take into consideration promotion of other forms of help such as routine, exercise and consistent individual, group and family counselling and support are neglected (Schierenbeck et al., 2013; Talatala et al., 2020).

While *lack of resources* and *access* speaks to more physical aspects of psychosocial disability care, *lack of knowledge* speaks to the narrative about mental illness. *Lack of knowledge* focuses on the incongruence between Western understandings of psychosocial disability and treatment, and cultural and religious understandings of psychosocial disability held by many unique and different South African communities (Dockery et al., 2015; Padayachee & Laher, 2014; Schierenbeck et al., 2013). This incongruence makes it difficult for Western-trained doctors to come to a correct diagnosis and leads to a general distrust of Western medicine within the community, leading to a preference for treatment through traditional healers(Bulbulia & Laher, 2013; Schierenbeck et al.,2013). These conflicting attitudes also contribute to the stigma surrounding psychosocial disability and furthers individuals' reluctance to seek treatment for their psychosocial disability (Dockery et al.,

2015). As a result of these lacking narratives and underdeveloped avenues of care for individuals with psychosocial disability in SA, the burden of their carefalls onto their family members and the community at large.

2.3 Family caregiver burden

Family involvement in the care and management of psychosocial disability is a very nuanced issue. On the one hand, studies have shown that family involvement in management of psychosocial disability is important and needed, especially because of the historical deinstitutionalisation of mental healthcare patients, which has discharged patients back into the care of their communities (Bonsu et al., 2020; Hendricks, 2014). On a basic level, many individuals with psychosocial disabilities have low productivity levels and low income, thus relheavily on family members to provide lodging, transport, and finance for medicationsand treatment (Yusuf et al., 2009). Beyond the practical, family members also act as caregivers, meaning that they attend to the daily needs of the individual with the psychosocialdisability with no expectation of compensation (Dockery et al., 2015). Family caregivers provide emotional support, as well as a sense of understanding and help with everyday functioning, particularly in cases where the psychosocial disability can be all-consuming (e.g., schizophrenia and bipolar disorder) (Rose et al., 2002; Yerriah et al., 2022). Family caregivers provide a safe space and act as a link between the individual with the psychosocial disability and the community, helping the individual to feel less isolated and "reintegrate into society" (Bonsu et al., 2020, p.36). Research has also found that early family involvement decreases the likelihood of individuals finding harmful alternative pathways to deal with their symptoms (Bonsu et al., 2020). Furthermore, positive family attitudes towards psychosocial disability and treatment have been found to increase treatment seeking behaviours by the individual with a psychosocial disability, as well as their medication compliance and their consistent attendance in therapy (Dockery et al., 2015).

On the other hand, the barriers to mental healthcare (discussed previously) put a huge financial and emotional burden on the family (Schierenbeck et al., 2013). These circumstances may contribute to a home environment that is not conducive to the management of psychosocial disability and may be so burdensome that the caregivers themselves show symptomsof a psychosocial disability (Yerriah et al., 2022; Yusuf et al., 2009).

In multiple studies, caregivers have reported a variety of negative experiences with psychosocial disability. Caregivers face a financial burden as a result of expensive

medication, treatment, and transport (Addo et al., 2018). These pressures are further extendedby living expenses, the caregiver's limited time and availability for other people and their life, job rescheduling and reduced working hours, all arranged in order to meet the needs of their family members, who in many cases will be dependent on them for the rest of their lives (Yerriah et al., 2022; Yusuf et al., 2009).

A lifelong dependency generates a spectrum of feelings for caregivers. Caregivers feel frustrated and resentful, which can cause a shift in family dynamics and result in domestic disputes (Rose et al., 2002). Simultaneously, caregivers experience intense feelings of guilt and helplessness at their inability to truly understand the experience of an individual with a psychosocial disability (Rose et al., 2002). Furthermore, families often feel as though they do not know enough about psychosocial disability, and the resulting symptoms and behaviour, inorder to monitor if their family member is regressing or benefitting from the treatment they receive (Jonker & Greeff, 2009; Rose et al., 2002).

Prolonged periods before or without treatment for individuals with psychosocial disabilities can worsen the symptoms for individuals, especially in psychosocial disorders with psychotic features (von Kardorff et al., 2016; Yerriah et al., 2022). Erratic, aggressive, and unpredictable behaviour, along with high rates of comorbidity in the form of substance abuse disorders, increases the stress, the burden and the energy exerted by caregivers to manage their family members (Engelbrecht & Kasiram, 2012; Yerriah et al., 2022). These periods also set the tone for increased rates of non-compliance, re-admissions, and relapses bythe individual with the psychosocial disorder, further entrenching the responsibilities of the caregiver (Yerriah et al., 2022).

While caregiving is a necessity for the management of an individual with a psychosocial disability, it can have a negative effect on the overall quality of life of a caregiver (Jonker & Greeff, 2009; Yerriah et al., 2022). Many studies have shown that long periods of caregiving are associated with increased stress, isolation from the community, lowered social interaction, a loss of a sense of self, susceptibility to physical diseases, lowered emotional wellbeing, and symptoms of both depressive and anxiety disorders (Jonker & Greeff, 2009; Rose et al., 2002; Yerriah et al., 2022; Yusuf et al., 2009). These consequences of caregiving, and the extent to which family members in the caregiver role are affected, are based on factors such as the relationship to the individual with the psychosocial disorder, age, and gender (Rose et al., 2002). Although the burden of psychosocial disabilities differs between family members, there is an even larger gap between the experience of psychosocial disability as a family unit versus

as acommunity. Harmful community attitudes about psychosocial disability further increases thepressure of care put on the family unit (Yerriah et al., 2022).

While ‘community’ holds connotations of unity, collaboration and support, psychosocial disability is not treated as a shared responsibility in many communities (Engelbrecht & Kasiram, 2012; Laher, 2014). While not all cultural conceptualisations of psychosocial disability are harmful, it has been found that across all cultural groups, negative cultural narratives minimise the importance and impact of psychosocial disability in comparison to primary healthcare issues (Dockery et al., 2015; Engelbrecht & Kasiram, 2012). Individuals with psychosocial disabilities and their family are often shamed, avoided, and isolated from the community. These families are usually seen as weak, vulnerable, other, are talked about despairingly, discriminated against for local jobs and opportunities and, in many cases, are targeted by criminals (Dockery et al., 2015; Engelbrecht & Kasiram, 2012; Rose et al., 2002; Schierenbeck et al., 2013). Understanding harmful community narratives about psychosocial disability can help address the root of a lot of the associated stigma and misinformation.

2.4 A Western conceptualisation of mental illness

The predominant lens through which psychosocial disability is engaged with in SA is through a Western framework, namely, a biopsychosocial perspective. A biopsychosocial perspective conceptualises psychosocial disability as an interplay between biological, psychological, and social factors (Kleintjes et al., 2013; Talatala et al., 2020). A biopsychosocial perspective is grounded in medical knowledge and depicts an individual’s dynamic interaction with the self, others and society, and is used to inform further engagement with- and treatment of- psychosocial disability (Babalola et al., 2017; Bulbulia & Laher, 2013; Engelbrecht & Kasiram, 2012; Padayachee & Laher, 2014). However, this framework does not meaningfully incorporate cultural conceptualisations of psychosocial disability into mainstream engagement with and treatment of psychosocial disability (Padayachee & Laher, 2014). This is because many cultural communities have different approaches to, and interpretations of, behaviours and symptoms associated with psychosocial disabilities that do not fit within the rigid biopsychosocial structure, and thus are less valued (Padayachee & Laher, 2014; Radhakrishnan, 2005). In other words, the biopsychosocial model underplays the role that culture and community has in shaping an individual and their experiences and understandings of psychosocial disability, which has implications for the relevance and effectiveness of mental healthcare in SA, discussed later in the dissertation.

2.5 Community conceptualisations of mental illness

'Community' speaks to a group of people with shared identity, knowledge, experiences, and values, but is a very broad term that can be applied to many different groups in society (Archary & Landman, 2022; Laher, 2014). SA has a history of oppression and segregation where individual identity revolved around race. However, in post-Apartheid SA 'race' is just the starting point of a variety of cultural groups (communities) with distinct beliefs, knowledges, traditions, and ways of life (Archary & Landman, 2022; Radhakrishnan, 2005). Viewing psychosocial disability through an exclusively Western paradigm denies the significance of other cultural understandings and the ways mental healthcare can be accessible and relevant to everyone in SA.

Studies have been conducted exploring the various cultural beliefs and traditions surrounding psychosocial disability in SA, with the focus being put on the perspectivesof three cultural groups, namely, the Hindu, Muslim, and Zulu communities (Ally & Laher, 2008; Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). Although each community has different principles underpinning their beliefs, cultural understandings of psychosocial disability seem to follow a similar framework in SA. Firstly, individuals are viewed as being compromised by three main parts: the mind, the body, and the soul (Laher, 2014). Secondly, this trifecta needs to remain in balance for an individual to have a fulfilling life. Thirdly, if there is any disruption to this balance it results in a mental, physical, and/or spiritual illness (essentially affecting mind, body, and/or soul) (Laher, 2014). Physical illness (a physical defect resulting in disease or physical injury) and mental illness (illness of a psychological nature) are understood in Western biomedical terms (Laher, 2014). Spiritual illness, on the other hand, is described as a third distinct category (Laher, 2014).

Spiritual illness encompasses the effects of external, non-physical forces that are 'supernatural' in nature (Laher, 2014). From a theoretical perspective, spiritual illness is a distinct category, as described above. However, in reality, the boundary between mental and spiritual illness is often blurry (Laher, 2014). The consequences of spiritual illness align with many symptoms of psychosocial disabilities. These include hallucinations, isolation, aggression, paranoia, fluctuations in emotions and behaviours, which are found in anxiety disorders, depressive disorders, schizophrenia, and psychosis (Ally & Laher, 2008;

Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). This thin border between these two illnesses means that there is acknowledgement from community members that spiritual illness can gradually turn into mental illness, and that sometimes mental illness is mistaken for spiritual illness and vice versa (Laher, 2014). Spiritual illness is also brought up in the mental illness space. For example, in psychotherapy, individuals will raise concerns that their behaviours could be as a result of callings from the ancestors (Padayachee & Laher, 2014). Therefore, as result of this overlap, when referring to 'cultural narratives' regarding psychosocial disability, this literature review will refer to this connection between mental and spiritual illness.

It is important to understand if the cultural narratives discussed above are relevant in a contemporary SA or are just historical summaries which are not applied practically in the everyday lives of South African Indian Hindus. Research on lived experience of psychosocial disability shows that a dual understanding and treatment of psychosocial disability exists within SA (Padayachee & Laher, 2014). It has also been shown that an astounding percentage (80-90%) of individuals "in developing societies", like SA, consult traditional healers regarding psychosocial disability (Laher, 2014, p. 192).

Studies regarding the experiences of Muslim and Hindu psychologists and traditional healers with their clients from Muslim, Hindu, and Zulu communities, reflect a duality when seeking ways to alleviate the symptoms of psychosocial disabilities. Essentially, individuals with psychosocial disabilities and their families from these communities seek both Western and traditional routes of treatment (Ally & Laher, 2008; Bulbulia & Laher, 2013; Laher, 2014; Padayachee & Laher, 2014). Western treatment is sought through clinics, psychiatrists, psychologists, medication and therapy, while traditional treatment is sought through traditional healers, rituals, and prayers (Padayachee & Laher, 2014). Studies also indicate the need for these individuals and their families to see practitioners who have knowledge of the cultural narratives of the Hindu, Muslim, and Zulu communities, respectively, and respect their holistic approach to treatment and care, as this deepens their connection, trust, and ultimately their disclosure (Bulbulia & Laher, 2013; Engelbrecht & Kasiram, 2012; Padayachee & Laher, 2014). Practitioners and healers alike recounted confessions of clients who have had very negative experiences with practitioners (most of which, but not all, who were trained in Western treatment modalities) who placed zero value on their cultural narratives and whose patronisation of their cultural experiences discouraged them from returning to seek care through Western avenues (Padayachee & Laher, 2014). The use of

both Western treatment and local cultural treatments in conjunction, and the high percentage of individualswho seek treatment or advice from traditional healers, confirms that cultural understandings play a major role in the engagement with psychosocial disability in each different communityin SA.

2.6 The South African Indian Hindu community

As mentioned, race is a starting point of the cultural diversity that exists within these communities and the country. The South African Indian community is no different. This community, although only making up about 3% of the country's population, is made up of different cultural groups, that contribute both economically and socially to the prosperity of SA and its status as a rainbow nation (Archary & Landman, 2022; Radhakrishnan, 2005).

Historically, South African Indians operated as indentured labourers under the British colonial system in SA, where they were treated as an indistinguishable non-white group thus negating all the complex issues of language, class, religion, and caste, -identifiers which were extremely important in their home countries (Radhakrishnan, 2005). During apartheid, stricter measures of segregation further consolidated identification structured along racial lines (Radhakrishnan, 2005). The Indian community as a whole strongly prioritised religious values, family connection, and strong work ethic as a means to maintain their connections to their countries of origin, to show their value, and essentially survive in a country where they came to be treated as middle tier (Archary & Landman, 2022; Radhakrishnan, 2005). Post-Apartheid SA provided greater social and financial opportunity and control for South African Indians, but also left them searching for their place and identity in a new integrated society under which they were no longer broadly classified as non-white (Radhakrishnan, 2005). The Indian community continued to preserve cultural values and principles that had created the foundation for them to forge their own unique path in the country (Archary & Landman, 2022; Radhakrishnan, 2005).

The present day South African Indian community can be divided into three main sub-groups, namely the Muslim, Hindu, and Christian communities (Bulbulia & Laher, 2013; Laher, 2014). Within the Hindu community, a clear distinction needs to be made between religion and culture, terms that often overlap. Hinduism is a religion that involves the belief in particular gods and the carrying out of specific traditions and ceremonies that honour these gods and their principles of life (Laher, 2014). But Hinduism is also an all-encompassing

philosophy and spiritual awareness that is enacted by everyday life, accepted norms, strong family values, and relationships, making up a cultural community (Laher, 2014).

The Muslim community follows this similar narrative of their specific religious beliefs translating into cultural practices and ways of life (Ally & Laher, 2008; Laher, 2014). The Christian community differs, in the sense that while they have particular religious beliefs that are distinct from Muslim and Hindu beliefs, Christian individuals in the South African Indian community may enact the cultural ways of life and understanding (e.g., the evil eye, witchcraft) of Hinduism (as Hinduism is also a philosophy of life), thus forming part of the Hindu community through a cultural connection, not a religious connection (Laher, 2014; Ojong, 2012). In other words, even though an Indian Christian individual does not believe in Hindu gods or religious narratives and even attends church and celebrates Christmas, they may still believe in spiritual illness in Hindu terms, and use certain methods (e.g., turning salt) to ward off negative spirits, as Christian beliefs of mental illness are exclusively Western, and do not always align with the lived experiences of South African Indians (Laher, 2014; Ojong, 2012). In the current study the focus will be on the South African Hindu community (i.e., followers of the Hindu faith and individuals who may not religiously identify as Hindu but whose every day actions are guided and informed by Hindu practices and cultural beliefs).

2.7 Literature gap

The reviewed literature has shown that there is, at a minimum, an outline of the cultural narratives of psychosocial disability in the Indian Hindu community in SA (Laher, 2014). There are also studies that have recounted the experiences of psychosocial disability from the perspectives of Hindu caregivers such as mothers, professionals and traditional healers (Bhana & Bhana, 1984; Laher, 2014; Padayachee & Laher, 2014). Although there has been research conducted in the Hindu community, it has been very limited, only amounting to a handful of studies (Ally & Laher, 2008; Bhana & Bhana, 1984; Kathree & Petersen, 2012; Laher, 2014; Padayachee & Laher, 2014). Additionally, caregivers' perspectives provide a specific interaction with individuals with psychosocial disabilities (Bhana & Bhana, 1984). These perspectives do not extend to all family members living with individuals with psychosocial disabilities, whether or not they are defined as caregivers, which is vital in a community that prioritises family relations (Radhakrishnan, 2005). The literature addressing experiences of psychosocial disability is also quite dated (e.g., Bhana & Bhana, 1984).

Collecting current experiences of psychosocial disability can elucidate the dual life that many South African Indian Hindus live today. This cultural group is trapped between respecting the traditions and expectations of 'elders' in the community, and the pressures of a more Westernised environment where beliefs about wellbeing and health are understood from a more biopsychosocial perspective (Padayachee & Laher, 2014; Radhakrishnan, 2005). Current interest and research can also lead to more culturally relevant methods of treatment of psychosocial disability in this cultural community.

2.8 Research Questions

Based on the reviewed literature, the following research questions were developed:

1. How do members of the South African Indian Hindu community, with a family member that has a psychosocial disability, understand and experience psychosocial disability?

a. How do South African Indian Hindus with family members that have psychosocial disabilities define psychosocial disability?

b. How do South African Indian Hindus with family members that have psychosocial disabilities understand psychosocial disability in the context of their own culture?

c. What is the experience of South African Indian Hindus who have family members with psychosocial disability?

CHAPTER 3: METHODOLOGY

3.1 Research design

'Psychosocial disability' is a very broad term incorporating many disorders (Kleintjes et al., 2013; Talatala et al., 2020). Consequently, engaging with 'psychosocial disability' in a research study has the potential to elicit a number of significant and layered themes (namely, stigma, lack of resources, lack of visibility, unity, culture, mental health policy etc.) that intersect with each individual and their identity very differently (Ally & Laher, 2008; Lund et al., 2012; Padayachee & Laher, 2014; Schierenbeck et al., 2013). It was, therefore, important in this study to use frameworks that reflect the complexity of the topic. The study used a qualitative research design and adopted an explorative and interpretative framework.

Qualitative research is flexible, dynamic and focuses on the collection of subjective data that captures the nuanced experience of being human and occupying specific social spaces (Fossey et al., 2002; Ward et al., 2018). It also involves the use of methods such as in-depth interviews that are not rigid in their application but rather accommodating of the unpredictability and volume of data that discussions involving participant experiences, and perspectives can produce (Adeoyo & Olenik, 2021). Furthermore, a qualitative research design allows for full context to be built of a phenomenon (Ward et al., 2018). Thus, a qualitative research design was the most appropriate design to use in this study. While this is most appropriate, there are limitations within this framework which include it being time-consuming and involving a laborious process of recording and analysing the volumes of data with complete reliance on the individual skills of the researcher (Anderson, 2010). However, these limitations were outweighed by the appropriateness of the design.

Much like a qualitative framework, an explorative research approach is adaptable in nature and emphasises the investigation of novel data. It looks to find new insights into an un- or under- explored phenomenon (Ward et al., 2018). This is particularly relevant to the current study as it focused on the experiences of an under-researched demographic, especially in relation to psychosocial disability. While an exploratory framework is the broader tool used in scaffolding research, an interpretative framework can be the means through which the subjective material can be understood, especially with regards to experiences and cultural understandings expressed by individuals in this specific social group (Babones, 2016; Ward et al., 2018). An interpretative framework focuses on assigning significance to, and constructing realities from, subject experiences, community interactions, and knowledge

produced by individuals and social groups (Babones, 2016; Ponelis, 2015). This framework seeks to take subjective material that can seem abundant and borderless, and anchor it by deciphering from it, the culturally reflective and relevant meaning, which aligned with this study's research aims (Babones, 2016). These more flexible designs may generate in-depth data but also have the potential to produce an overwhelming amount of data. Additionally, this design specifically requires heavy interpretation which is intrinsically linked to the researcher's personal experience, perspective, and knowledge, which could be limited (Queirós et al., 2017). How these potential challenges were managed will be discussed further in the trustworthiness sub-section of this chapter.

3.2 Sample and sampling

The sample consisted of six participants, which is typical for this type of research design (Gill, 2020). As discussed earlier, the Hindu community in South Africa is a heterogenous cultural group (Bulbulia & Laher, 2013; Laher, 2014). Therefore, the inclusion criteria required participants to be members of the South African Indian Hindu community, initially exclusively residing in Johannesburg. The study was later expanded to include members of the South Africa Indian Hindu community who resided anywhere in South Africa because it was difficult to find individuals willing to participate in the study from Johannesburg. Potential reasons for this limited participation will be shared in the limitations of the study in the final chapter. The participantsneeded to be 18 years or older as the content dealt with in this study is potentially sensitive and required participants to grasp the intricacies of psychosocial disability (Balen et al., 2006). Additionally, this age range does not require further consent from a parent or guardian(Balen et al., 2006). Participants should not have been officially diagnosed with a psychosocial disability themselves as it was felt that this would have complicated the analysisof the data since having a psychosocial disability adds a different layer of understanding to the experience of this form of disability (Jonker & Greeff, 2009; Rose et al., 2002). As a result of limited participation in the study, one of the participants who disclosed during the interview that they did in fact have an undiagnosed psychosocial disability, namely anxiety, was kept as part of the study. This addition was kept in mind during data analysis.

Literature indicates that experience of disability has been looked at through mostly parental relationships, while other familial relationships with psychosocial disability has been less explored (Ally & Laher, 2008; Bhana & Bhana, 1984; Laher, 2014; Padayachee & Laher, 2014). Therefore, the participant could have had any familial connection to their family

member with a psychosocial disability (e.g., mother, cousin, aunt). Furthermore, different familial relationships involve a range of responsibilities and expectations in relation to the family member with the psychosocial disability, thus translating into a variety of different experiences with psychosocial disability (Rose et al., 2002). Capturing these experiences aligns with the exploratory research design which seeks to bring more depth to under-explored perspectives (Ward et al., 2018). Initially, participants needed to be living in the same household as their family member to ensure direct involvement and experience with their family member with the psychosocial disability, but the study was expanded to include participants who did not currently live in the same households as their family members. This criterion was expanded as many of the individuals who were willing to participate in the study had for many years before but were not currently living with their family member. Furthermore students, who seemed to be the most willing to participate, moved between their household with the family member and their university at different times throughout the year.

Suitability of participants for this study extends to the family member with the psychosocial disability that participants reported on. While family members of participants needed to have had a psychosocial disability for a minimum of three years (to establish that the participant has had enough exposure to the psychosocial disability), they did not have to have been officially diagnosed with a psychosocial disability by a Western medical health professional. As per the literature, many individuals in the Indian Hindu community either do not seek assistance or seek assistance from traditional healers for their psychosocial disability and may never meet with a medical health professional to receive an official diagnosis according to the *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-5) (American Psychiatric Association, 2013; Padayachee & Laher, 2014). Furthermore, the family member needed to be within the age range of adolescents to adulthood, as diagnosis of a psychosocial disability is more likely to be unclear, progress, or change during childhood (Balen et al., 2006). The inclusion criteria were kept realistic for the short period of time in which the study was run.

Participants were sampled using purposive non-probability sampling techniques, which is a qualitative method that involves the specific selection of participants who align with the criteria and subject matter of the study. Selecting participants in this way is both cost- and time-effective and useful in studies where there is a limited number of data sources available (Etikan & Babatope, 2019). This allowed for the direct recruitment of individuals that match the inclusion criteria of the study and was most efficient in the study's limited

time-period. This initially included an advertisement (please see Appendix C) that was circulated on both mine and my colleagues' social media sites (such as Instagram and Facebook). My colleagues and I have a large and racially diverse social media following. My colleagues, specifically, have a following of individuals from within Johannesburg. The advertisement was also distributed among the members of related organisations such as: the University of the Witwatersrand Hindu Student Society (Wits HSS) and a public Facebook group called Gauteng Hindus. These virtual and in-person spaces often act as a place for the Hindu community to come together for prayer, support, and recreational activities. Additionally, the supervisor Dr Clare Harvey, a clinical psychologist, contacted her colleagues who could potentially put me in touch with more participants. Once contact was made with the first few participants, further participants were found through snowballing, a technique used in novel or niche areas of study whereby participants (who can otherwise be difficult to recruit) are sought based on the recommendations of current participants (Etikan & Babatope, 2019). In this study, snowballing took the form of current participant referrals.

Although many avenues were used to advertise the study, participants were challenging to find, resulting in a sample of six participants. This could speak to the South African Indian Hindu community's reluctance to discuss psychosocial disability because of stigma and lack of knowledge, and unfamiliarity with the term 'psychosocial disability'. It could also speak to the limiting inclusion criteria of the study which initially required the participants to be living with family members with the psychosocial disability. This is not always a reality (especially for students) and not representative of the everyday interactions that do take place between family members of the Hindu community even if they do not live together. Another factor that may have discouraged individuals from participating is my name. 'Sumaya Habib' is a common and typically Muslim name which may have given potential participants the impression that I was in fact Muslim. This may have caused them to see me as an outsider or with the potential to invade and make judgements about the community concerning the sensitive issue of psychosocial disability without having any knowledge of the customs or culture, thus increasing the reluctance to participate.

Table 3.2

Demographics of participants

Participant	Age	Gender	Race	Religion	Place of residence	Family member with psychosocial disability	Perceived psychosocial disability of family member	Length of time living with family member
A	21	Female	Indian	Hindu	Johannesburg	Brother	Attention-Deficit/Hyperactivity Disorder (ADHD)/ Bipolar Mood Disorder	10+ years
B	54	Female	Indian	Christian	Durban	Uncle	Anxiety/Bipolar Mood Disorder	20 years
C	56	Female	Indian	Hindu	Port Shepstone	Mother	Anxiety Disorder	25 years
D	37	Female	Indian	Hindu	Port Shepstone	Aunt	Anxiety/Mood Disorder	10 years
E	48	Female	Indian	Christian	Durban	Daughter	Major Depressive Disorder	18 years
F	21	Female	Indian	Hindu	Port Shepstone	Sister	Anxiety Disorder/Eating Disorder	18 years

3.3 Research instruments

This research study used one-on-one, semi-structured, in-person and online interviews (please see Appendix B). Semi-structured interviews use a flexible framework comprised of mostly open- ended questions, followed by relevant prompts, to elicit information from participants surrounding a broad topic area. This structure encourages some degree of agency in the flow of the conversation and the rich data produced by the participant (Etikan & Babatope, 2019). Semi-structured interviewing is a common qualitative tool that allows deeper exploration andeach interview to be unique and shaped by the participant, offering a nuanced perspective of the same issue (Elliott & Timulak, 2015).

The semi-structured interview schedule addressed the gap found in the literature, relevant to the scope of the study and was drawn up after reviewing the relevant literature on the topic (Etikan & Babatope, 2019) (please see Appendix B). The guide used mostly open-ended questions to allow participants to express their inner thoughts and experiences freely without limiting the data each participant can contribute, but also included some structured questions to keep the conversation within the scope of the research aim (Adeoyo & Olenik, 2021; Etikan & Babatope, 2019).

Interviews took place in-person at a time and place suitable for participants, which included their homes, in their areas of living, or using rooms at the Emthonjeni Centre at the University of the Witwatersrand booked prior to the interview. Interviews were also carried out through the online platform of Zoom, when in-person interviews were not possible (mainly for participants who lived outside of Gauteng). Audio recording equipment was used for all interviews. A password protected computer was used to transcribe the interviews verbatim and to store the recordings and transcribed interviews.

3.4 Procedure

Upon receiving ethical clearance for the study from the Human Research Ethics Committee (non-medical) at the University of the Witwatersrand (please see Appendix A), the advertisement for the study was sent out via the social media platforms of Instagram and Facebook. Furthermore, Dr Clare Harvey sent it out to her colleagues. To recruit the necessary number of participantsfor the study, snowballing, through other participants' referrals was also used. The advertisement (please see Appendix C) displayed the title of the study, a summary of what participation entails, the platforms through which interviews were run, and researcher contactdetails. Individuals showing interest in the study received a participant information sheet (please see Appendix D) via email outlining, in more specific detail than the advertisement, what the study entails, the guidelines of engagement, their ability to leave the study at any time up until the end of data collection if they feel uncomfortable (voluntary participation), and the contact details of myself, my supervisor and of the free counselling services. Once the participant had emailed me showing understanding and confirming their participation, their contact details were captured, and the time and place of their interview was arranged viaemail or mobile phone.

Prior to the interview, the participants were asked to sign a consent form (please see Appendix E) and were briefed on what the interview session would involve. They were

assured of confidentiality and reminded that the interview session would be audio recorded. It was also emphasised that they could leave the study up until the end of data collection if they felt uncomfortable. The semi-structured interviews were between 35 minutes to 60 minutes long, in which the participants' responses were captured by audio recordings. After the interview the participants were thanked, debriefed, and encouraged to contact any of the free counselling services provided on the participant information sheet if the interview or research process made them feel emotionally triggered or uncomfortable. After the interviews, the data was transcribed verbatim and stored on a password protected computer. Final anonymity of participants was ensured by using pseudonyms for each participant, altering minor details about their lives and/or their family members with psychosocial disabilities and not revealing any specific, easily identifiable information. Additionally, the supervisor only had access to the transcribed interviews, not the original recordings. The data was then analysed using thematic analysis (TA).

3.5 Data analysis

At the conclusion of transcription, Braun and Clarke's (2020) thematic analysis (TA) model was used to analyse the data. Thematic analysis is a common tool used across frameworks in qualitative research (Ibrahim, 2012). It acts as a structured way of reviewing subjective material but also being flexible and led by the data (Braun & Clarke, 2006; Ibrahim, 2012). While Braun and Clarke (2022) state that TA can be split into three main approaches, namely: coding reliability approach, codebook approach, and reflexive approach, the reflexive approach was seen as most suitable for this study as its ten core underpinnings align most with the framework and aims of the study. With reflexive TA, coding can be performed by a single coder as opposed to a collaborative effort, acquisition of 'objective data' is not seen as possible since the collected data from participants (subjective experiences and understandings) and derived themes by researchers are naturally underlined by subjectivity. Similarly, interpretation of the data can never approach increased objectivity the more the researcher becomes immersed in the data but can either be "weaker" or "richer" depending onthe time and effort the researcher puts into analysis (Braun & Clarke, 2022, p.9). "Richer" data can be produced through the interplay between deep immersion with the data, and time away to think and reflect on the themes produced (Braun & Clarke, 2022, p.9). In reflexive TA the themes are developed from the data (i.e., according to what the data reveals, as opposed to premediated or earlier developed themes). The themes do not organically emerge but rather are "produced" by the direction/interpretation of the researcher,

which is helpful in terms of keeping within the scope of my research question. Additionally, there is an emphasison the need for the researcher to reflect on their own stance, which is particularly important in avoiding bias in a study so personally related to my own experience (Braun & Clarke, 2022).

Practical steps that were taken to organise the data followed Braun and Clarke's (2006) six-step process for TA. This process begins with 'familiarising' oneself with the data by firstly transcribing and then reading through the content extensively, it then progresses to the 'generation of initial codes' by systematically dividing the data into smallerpartitions (coding) of related information which through comparison with each other and the entire data set as a whole evolves into the creation of preliminary 'themes'. These themes arethen interrogated, analysed, removed of repetition and refined until the final compilation of relevant and related themes that reflect the research question(s) can be discussed in the final report (Braun & Clarke, 2006).

3.6 Ethical considerations

This study required ethical clearance as it involved human participants. I applied for ethical clearance from the Human Research Ethics Committee (non-medical) from the University of the Witwatersrand (please see Appendix A). Once ethical clearance was received, participant recruitment began. During recruitment, participants were given enough space and time to respond to the advertisement with no intended forms of pressure, manipulation, or coercion being used to secure participation from potential participants. Prior to the arranged interview, participants were required to sign a consent form (please see Appendix E), which contained: the title of the study, a brief description of what the study entails, reminders regarding confidentiality and voluntary participation, the contact details of myself and the supervisor, and the contact details of free counselling services. The participants were informed that signing the consent form indicates their acceptance of the conditions of the study and their voluntary willingness to participate. The participant information sheet, the consent form, and my briefing prior to the interview emphasised the interview process, confidentiality, voluntary participation, the audio recording, and the free-counselling services.

During the interview all participants were treated with respect and empathy, following the ethical conventions of the interview space (Rabionet, 2014). In the event that participants did feel any discomfort, my clinical skills were used to comfort them initially and then they were guided to use the free counselling services listed on the participant information sheet

(please see Appendix C) (Harvey, 2017). Although most of theparticipants are not considered a vulnerable group (as it is their family members, not them, that have the psychosocial disability), the interview may have elicited sensitive information that could have triggered an emotional response from the participants. Therefore, the inclusion of contact details for free counselling services and the use of my own clinical skills was necessary as protective measures for participants. Interviews took place either in safe, secure and private rooms at a convenient place for the participant or in the Emthonjeni Centre at the University of the Witwatersrand. Interviews were also held on the online platform of Zoom, where a unique password and ID were needed for each participant and me to access the meeting. I ensured that I was in a secure individual space for online interviews. After the interview the participants were debriefed (please see Appendix B), which also gave them a chance to process the previous interaction and voice any concerns. I ensured that they felt emotionally comfortable finishing the interview.

Complete anonymity could not be achieved as the interviews were face-to-face, or online which comprised participant identity. However, final anonymity of participants was ensured as during the transcription process the names of participants were replaced with pseudonyms, minor details of both the participants and their family members were changed, and easily identifiable information was removed. Both recordings and transcripts were kept on a password protected computer. I had access to the original recordings, while my supervisor only had access to the anonymised, confidential transcripts.

3.7 Research Reflexivity

Engagement with data in qualitative studies requires subjective understanding and interpretation from both the participant and researcher. Reflexivity is an important tool used to evaluate the influence that the researcher has on the participant and data at different points of the research process (Bott, 2010). In the interview process, regardless of the empathy, compassion and interview conventions applied,there is an uneven power dynamic between the researcher and the participant (Anyan, 2015; Rabionet, 2014). The participants need to feel that, despite this dynamic, their thoughts and expressions are being respected and that they have agency in the space (Anyan, 2015). Enabling this agency for the participant can occur through the assessment of how my identityis translated into the conversation with the participant (Anyan, 2015; Bott, 2010). Interactionswith my identity in the interview space could have been positive, for example, my

'Indianness' may have made participants feel that I innately understood the cultural world from which their experiences are drawn, thus eliciting richer responses. However, my identity may have intersected negatively, for example, my position as a student clinical psychologist may have been perceived as academic, distant and may have made participants feel judged. Being aware of the role that identity plays in the interview space helped me be realistic about my impact on the research, which is inevitable (Cassell, 2005).

My identity in relation to my own thoughts, understandings, feelings, and experiences also come into play, especially within an interpretative framework (Bott, 2010). I come from an Indian community where my experiences with, and understandings of, psychosocial disabilities have been intricately linked to cultural knowledges. However, interpretations of the generated data cannot be sourced from within the narrow confines of my experience, but rather led by the participants' narratives. An interpretative framework emphasises that subjective material relayed by the participant should be taken at face value and that it should not undergo rigorous interrogation or align with any specific theory or initial assumption (Babones, 2016).

This condition of the interpretative framework showed the need for me to continuously examine my thoughts, feelings, and perspectives before, during, and after the interview process, especially with regards to participants whose personal accounts resonated with me. This process occurred through personal journal entries throughout the research process and regular supervision meetings with Dr Clare Harvey. Limited perspective was also addressed by reading literature and educating myself on the features of the various psychosocial disabilities, and different cultural aspects related to psychosocial disability, so that my understanding was not exclusively from my specific interactions, but from credible sources that could provide other useful perspectives.

During data analysis, this process of self-reflection, accountability and furthering knowledge became extremely important. Although TA has a standard structure through which data is organised, to some extent determining which data is significant enough to become a 'theme', depends on one's own interpretation of the information (Braun & Clarke, 2006). The themes needed to reflect the significance revealed in the current data, as opposed to data selected to fit into what I have internally constructed as significant. Identifying my bias and being transparent about my thought process, throughout the research process helped

in locating any bias that may have underpinned the themes created during analysis. This could then be addressed and referred to in the discussion on the limitations of the study.

3.8 Trustworthiness in Qualitative Research

The subjective nature of qualitative research leaves it open to scrutiny regarding reliability and validity. However, these concepts do not align with the goals nor the nature of qualitative research such that importance has been placed on the maintenance of other measures, namely: transferability, credibility, dependability, and confirmability. These measures are seen as more congruent with qualitative research to ensure that the research is conducted methodically and with rigor, resulting in a meaningful and trustworthy process (Cope, 2014; Shenton, 2004)

Transferability refers to study findings being relatable to outside individuals not involved in the study (Shenton, 2004). This measure does not speak to 'generalisability' in the same sense as a quantitative study. Rather transferability refers to the study's aim to provide the readers with knowledge of the participants and of how the study was conducted, which would allow readers to contextualise the study fully and be able to relate to the experiences of the individuals of the phenomenon, as well as create their own meaning from what they have read (Cope, 2014). This measure was upheld by fully contextualising the social group from which participants were selected and the type of individual that was selected as a participant and providing clear descriptions on how interviews were conducted (Shenton, 2004).

Credibility refers to how congruent the research findings are with reality (Cope, 2014). This was upheld by firstly using research methods that are well established as part of a qualitative framework (Cope, 2014). As an Indian woman who is part of the South African Indian Hindu community I had familiarity with the cultural group from which participants were selected, which allowed me to engage with participants from a position of intimate understanding and recognition. But I also refamiliarised myself with older and contemporary literature regarding spiritual and cultural practices in this community (Cope, 2014). Honesty from participants also formed an important part of credibility and was upheld by encouraging them to be honest, frank, and emphasising that there were no correct responses rather that the study was based on their personal experiences (Cope 2014). Scrutiny by my supervisor of the authenticity in the engagement between me and participants, through the review of transcripts, also helped play a role in upholding credibility (Cope, 2014; Shenton, 2004).

Dependability refers to the constancy of data over similar conditions (Cope, 2014). This was upheld by maintaining a consistent standard throughout the research process, maintaining the same basic conditions for each participant, and being clear and precise about the procedures involved (from the research design to data collection and analysis) in the write-up such that the study could be replicated with similar participants in similar conditions. This also involved reflecting on the "effectiveness of the process of inquiry taken" (Cope, 2014; Shenton, 2004, p.72). These aspects should ensure that if the research is reviewed in the future, a future researcher will be able to see that the correct protocols have been followed (Shenton, 2004).

Confirmability stresses the importance of the study results (themes and interpretations) being representative of the experiences and accounts of the participants and not being exclusively derived from the preferences or viewpoints of the researcher (Cope, 2014; Shenton, 2004). This was upheld by interrogating bias and practicing reflexivity throughout the research process and in the write up of the report (Cope, 2014; Shenton, 2004). It was also upheld by clearly documenting the research process and analysis and justifying the choices made (e.g., the research framework and design) as well as by actively pointing out potential weaknesses in design choices (Cope, 2014; Shenton, 2004). The interpretative choices made during the write up of the discussion of the themes were also substantiated by the rich quotes from participants that were presented in the findings section (Cope, 2014; Shenton, 2004), to follow.

CHAPTER 4: FINDINGS

Six participants were interviewed about their understanding of, and experience with, psychosocial disability in relation to their family member with a psychosocial disability, specifically within the context of the South African Indian Hindu community. The data from these interviews were transcribed, analysed, and organised into meaningful themes. Overall, three broad themes were identified, namely, 'layered understanding of psychosocial disability', 'secrecy and stigma', and 'family experience'. Two of these broad themes were further broken down to address the nuanced issues within them. 'Layered understanding of psychosocial disability' was broken down into three subthemes: 'cultural versus biomedical', 'generational', and 'gender'. 'Family experience' was broken down into the two sub themes of 'family responsibility' and 'family emotional response.'

4.1 Layered understanding of psychosocial disability

In the South African Indian Hindu community psychosocial disability is engaged with from different perspectives. Participants spoke about two main understandings that they have experienced: one being a cultural understanding (understanding psychosocial disability through the lens of religious and traditional beliefs) versus a biomedical understanding (viewing psychosocial disability as an interplay between biological, psychological, and social factors), each influencing a mindset about psychosocial disability and the avenues of treatment taken. The different understandings were further linked to generational differences in the community. It also emerged that the topic of psychosocial disability was engaged with differently depending on gender.

4.1.1 Cultural understanding versus biomedical understanding

A cultural understanding of psychosocial disability places the responsibility on the individual experiencing the disorder (Padayachee & Laher, 2014; Laher, 2014). This understanding views the source of an individual's psychosocial disability being as a result of the individual having done something wrong in their life orr that someone else has wished something negative or evil towards them or as a consequence or punishment for a transgression that theirclose family member (such as their parents) has committed (Padayachee & Laher, 2014; Laher, 2014). Thus, individuals with this understanding seek treatment or solutions for psychosocial disability through cultural avenues such as prayer, fasting, and visits to traditional leaders. These individuals see psychosocial disability as a problem and, thus, treatment is solution orientated.

The prominence of cultural understandings of psychosocial disability in the South African Indian Hindu community was acknowledged by most participants. Participants discussed different aspects of cultural understandings of psychosocial disability. Participant A said,

I don't know if it is because we are like a diaspora community or like what happened here. But I feel like in this case it's [traditional mindsets about psychosocial disability] hindering it a lot. It feels like these cultural knowledges, are just used to generalise situations instead of looking at an individual, um, to be like: 'okay this is what's happening with this specific person'. They're just blaming it on what they would understand as like a general situation and they like use their ideology like, like the evil whatever.

Participant F spoke about the mindset regarding psychosocial disability that she had experienced, particularly from elders in the family,

...having these psychosocial disorders then you need to go and like I said, you need to fast, you need to make prayers, you need to do, like a whole, sha-bang basically just to try and get rid of it, although obviously you can't get rid of it easily because it's something that you're suffering with.

Participant F went on to speak specifically about the concept of karma:

... what I've come to hear from bits and pieces from obviously the elders speaking, is that people that tend to have psychosocial disabilities or in their case 'problems', they are dealing with it because of karma and not necessarily because of their karma. Like if it's the youth that is going through these issues for what the parents… had done in their lives.

Participant A shared her experiences with elders in the family by speaking from their perspective, *"...oh you got like an evil eye, it's because of somebody else and that you just need to pray away that kind of negative' ... Like it's not your own perspective, it's something that someone's put on you."*

Participant A also spoke about the avenues her brother was pushed to take in the management of his psychosocial disability:

...astrologically, these are the days he must fast and the prayers he must do…he

didn't really keep up with it and then that was kind of like implied: 'oh, that's why it's not working out. You didn't complete the prayer you were supposed to do.' 'And you're supposed to do this prayer every day. Every week for the rest of your life,' like it's not meant to end.

Participant C spoke about how cultural understandings of psychosocial disability played a large role in her life despite it not aligning with her own (or even her parents') beliefs:

There was always that dimension with family members who were religious and trying to say, 'Okay, you need to do this prayer, you need to do that or you need to take her to this spiritual person'. So there was always that pressure that put my mom and dad in an awkward position because it was like, 'OK, we need to resolve this but doing that doesn't quite fit in with our beliefs', so there was always that dimension and they had to kind of, and of course they had to be grateful to family members for stepping in.

Participant C went on to say that it may have been a matter of accessibility when it came to treating her mother:

'Oh okay, she should see a therapist. She should…' I don't even know if that option was available. The easiest option was the most accessible would be this kind of I don't even want to say spiritual, but this religious kind of intervention that was supposed to heal everything. And I mean we, there was a lot of travelling involved because, you know, an auntie would decide this person was the best person [traditional healer] and someone else was the best person, so it was also a lot of inconvenience in that, like I remember, we had to travel to Transkei [rural area] sometimes.

Often individuals with a more cultural mindset regarding psychosocial disability do not understand the very real ways in which psychosocial disability influences one's mood, functioning, and behaviours, misinterpreting the behaviours as laziness, rudeness, defiance, or even low intellectual capacity. When speaking about her grandmother, who is a traditional leader in her community, participant A said,

And I view it [the Hindu community] as very traditional. She doesn't really have much understanding of these kinds of issues [psychosocial disability]. Yeah. So again, it comes, kind of comes down to feeling a bit like they, they treat it like he's [her brother]

making an excuse rather than it being like an actual reason. I feel like that's kind of applies to like most of the traditional leaders that we have except for that one priest.

She went on to say:

...and so with the more traditional people, I don't think they think about that kind of stuff. Yeah. That much. Or they, in their mind it would just be a thing of just, you know, "pray it out" kind of thing. They don't think about the actual changes and actual things that need to be done in real life to address those things. It's just a, a mentality thing to them.

Participant D echoed these sentiments when talking about her aunt's interactions with her elder siblings, *"So the youngest is the one that I'm talking about now. And it takes its toll because they [her aunt's older siblings] don't understand. They always see it as, 'She's doing things purposefully'."*

Participant A talked about cultural understandings and the negativity surrounding that understanding from a slightly different and interesting point of view. She spoke about the continued traditional lens through which many members of the South African Indian Hindu community see psychosocial disability, as being a way of the community maintaining traditional values. She further spoke to how in India these traditional mindsets about psychosocial disability have evolved and changed to be something more modern. Participant A said:

...with like diasporic communities where they're just a little bit more old fashioned because they're trying to hold onto all the stuff and they're not very good at adapting to like modern days. Whereas, um, from like interactions of like the general Indian community or like the Hindu community that's based in India, they've been able to adapt. They apply cultural knowledges and things to modern situations.

She emphasised the dynamic in South Africa by saying:

...like the Hindu community is being very open about mental illness and things, but like those based in India versus South African people who kind of still view it as a bit of a, I don't wanna say like a stigma, like they don't say it as something bad, but they kind of view it as if it's something that doesn't exist or like something that's, you know, um, a, a myth kind of thing or something that they downplay a lot.

Participant A did not dismiss the importance of cultural knowledge, rather she spoke about the potential for incorporating cultural knowledge in the community's engagement with psychosocial disability in a more helpful way,

...I do feel like there's certain like cultural knowledges that are like encourage people to, you know, like look inwards and it encourages them to like seek supports and things. But I feel like that hasn't really been translated into like, at least my community or at least South African Indian communities.

While most participants spoke about being in environments where cultural understandings of psychosocial disability were prominent, participants themselves did not necessarily have this mindset nor agree with this conceptualisation of psychosocial disability. Participant B said,

I don't believe in that [?]. I think that is about the individual itself and just like how we have different types of sicknesses in our lives, I think it's just something that comes at certain times as if we have to say 'it's because of religious' or 'it's cause of family', 'because of anybody'. I don't think we can pinpoint mental illness onto anybody.

Many participants spoke about their understanding of psychosocial disability being from a more biomedical perspective. A biomedical understanding of psychosocial disability is one that takes into consideration the biological, psychological, and social factors that can lead to an individual having a psychosocial disability. As a result individuals seek treatment through biomedical avenues (such as a psychologist, a psychiatrist and/or medication), understanding to some extent that psychosocial disability and its management is a longitudinal process with many moving parts. This understanding was seen by participants as a more modern understanding and linked to the younger generation in the South African Indian Hindu community, which will be explored in the next sub-theme.

4.1.2 Generational

Understandings of psychosocial disability in the South African Indian Hindu community are very layered not only from the perspectives of cultural versus biomedical but also generationally. There was a clear trend reported by participants of cultural understandings of psychosocial disability being associated with the older generation, whilst a

biomedical understanding of psychosocial disability being associated with the younger generation. Participant A said,

I don't feel like they [older individuals] are very aware of it, cause I feel like an understanding of like psychosocial issues are, is a very new age thing. It shouldn't be, but it's a thing that's kind of just been focused on it more in younger generation.

In comparing the two generations, Participant F said:

…with our generation I have seen a change of where we are talking about this more …in a few cases I've recently seen is that the parents in that generation is being more open towards it very slowly, but they are taking a change and trying to understand and engage with us a little." Participant D said,in reference to addressing psychosocial disability, *"But if I look at my nieces or nephews, forexample, they would say, 'OK, you should see a doctor'…that's the first thing they would say. Whereas if you look at my aunts and uncles, that's not the first thing that they would say, for example.*

Participant D went further to suggest a reason for the diverging mindsets about psychosocial disability, *"So yeah, I would say yes, the youth, the younger generation does place more, what should I say, trust in the medical community, whereas the older generation does not."*

Many participants ventured that exposure to knowledge about psychosocial disability was a possible reason as to why there was this divide in understanding across generational lines. Participant C spoke to how when she was young and her mother was having psychosocial disability episodes, psychosocial disability was not a very clear or talked about concept to them:

And also mental health. This was in the 80s, early 80s, maybe late 70s at some point. Mental health really wasn't a thing. I mean, nobody said, 'Mom was ill like that, you know, like she'd need to seek medical attention.' And I can't even think of a single psychologist or therapist that we could have turned to. It was the family doctor who prescribed medication for anxiety or had on sleeping tablets or something of that sort.

Participant F spoke about her parents' limited knowledge about psychosocial disability in comparison to her and her sister:

... like my parents don't know much about psychosocial issues compared to the amount my sister and I do and that's cause, I guess, like my parents are, I don't want to say different, but, compared to the Indian community, at least they allowed us to venture into these sort of things, even though they are considered taboo.

Participant F went on to speak about knowledge in general:

I don't think it's really spoken enough about. Like I feel like especially the older generation before us, they don't have an understanding much of it or on it. So they don't, they don't like elaborate on it, they don't teach us about it. It's like some of those things, they just don't talk about. You know, it's like when the elders are speaking you just have to be quiet and respect them, respect the decisions.

This generational aspect was reflected not only in the responses of participants but also in the interviews carried out with older participants. Although these older participants seemed to understand their family member's specific needs, moods, and periods of their psychiatric illness (for example participant B), they did not necessarily present as fully understanding the concept of psychosocial disability outside their family member. For example, they appeared to lack the knowledge of the names of conditions, and even the roles of professionals or facilities that their family members have received treatment from.

One of the suggested contributing factors to this more surface level understanding of psychosocial disability is limited exposure to knowledge about psychosocial disability. Participant F expressed that social media platforms, which older individuals do not frequent, play a huge part in exposure to, education about, and advocation for, psychosocial disabilities.

In terms of what that exposure to information about psychosocial disability looks like for the younger generation of South African Indian Hindus, participant F said,

I feel like as our generation, we were very exposed to a lot of things because of several aspects such as things you see on TV and social media, what we read, the schools we were in, we're exposed to a whole lot of stuff and scenarios. So we're going to experience and

talk about these things.

Participant F also relayed her experiences with the youth regarding psychosocial disability,

So obviously now with this saying you have like other students as well and you'll make friends and you branch out and you'll meet like a whole bunch of people and what I've come to know is that, especially in terms of the youngsters or the youth that we were called at the time is that a lot of us had anxiety of which our parents didn't necessarily understand.

Participant E spoke about how the isolating and anxiety-provoking conditions of the COVID-19 pandemic created an opportunity for individuals to speak more openly about their mental health struggles, enabling an increased exposure to- and discussion regarding psychosocial disability globally:

I think people have become a lot more aware now and more open-minded, especially during, after COVID and during COVID than what we've been through because there's been so much more talk about it now. I think prior to that, it's been a little bit more closed in terms of how open people are with how, you know open people are about what they're going through or what they're feeling, et cetera.

As seen above, participants presented a cultural understanding and a biomedical understanding of psychosocial disability as largely dichotomous, and then linked these two understandings to two distinct generations. However, it became clear that when speaking to participants who perhaps would be considered middle age (roughly between the ages of 37 and 48) , there was a sense of this generation having a dual perspective. This manifested as these participants respecting some aspects of cultural beliefs or at least feeling that spirituality was an important part of one's self and wellbeing (perhaps as a result of growing up in more traditional households) and continuing to use avenues of prayer and even fasting, but at the same time having exposure to more "modern" perceptions of psychosocial disability. They gained this exposure through social media, their jobs in healthcare or education, or even experience with their children and nieces or nephews (millennials) and were open to- and even encouraging others in their lives to seek assistance from medical health professionals. Participant D illustrated this by saying:

I'm not sure if I am classified as being older or younger, I think I fall in between, I'm

like an in between kind of phase so I kind of embrace both. But if I look at my nieces or nephews, for example, they would say, 'OK, you should see a doctor', You, you know. You know they, that's the first thing they would say. Whereas if you look at my aunts and uncles, that's not the first thing that they would say, for example.

Participant F said about the parents' generation understanding psychosocial disability by incorporating their children's perspectives,

…And I think, yeah, in in most often, obviously through the different stages of raising kids within, you know, depending when they were born from, from millennials, etcetera. There's definitely a shift in terms of parents and them understanding what's happening with their, with their children.

4.1.3 Gender

An aspect of engaging with psychosocial disability that emerged in the data was gender. Although gender was only discussed by two participants, the absence of male interest in the study and even referrals to potential male participants by other participants felt reflective of the minimisation of the male experience of psychosocial disability in the South African Indian Hindu community.

Participant A spoke to how there seemed to be a difference in the way that the South African Indian Hindu community handled psychosocial disability between young and teenage girls and boys. She spoke about how girls who opened up about having experienced any trauma and other social issues were encouraged to work through and express this trauma through traditional dance called Bharatanatyam,

...like a religious dance, so it's like I've noticed a lot of girls who have trauma, their parents push, tend to push them into that as like a way to channel this stuff. And I've noticed that it worked and it was like a lot of religious leaders that I've like seen have always encouraged [that].

While with boys, the sense was that they could not be open about their struggles with psychosocial disability. She said:

...with boys I've noticed it's just been a general, the shunning of issues….in Indian communities they tend to take social issues with girls a bit more seriously and I think it's just

because they assume like, they expect like an emotional response from girls whereas they expect the boys to just like, have your emotions but get over it and still be a man about it. So that's just also something that have that like, that very traditional mindsets kind of translated into the South African Hindu community. …there's a little bit more physical support for girls with mental issues.

Along similar lines, participant D spoke about a recent phenomenon in her hometown involving young men,

So recently in the last two years or three years, there have been lots of young Indian males committing suicide here. And I don't know if you've heard about it. …And if you look at the number of people that just, there's a lot of suicides that has happened. Like basically I would say over the last two years I know of at least 13 to 14 suicides that have happened.

Participant D speculated that this high death toll could be as a result of stigma attached topsychosocial disability, especially for men:

Perhaps it's because they are battling with something they don't talk about it and perhaps there is a stigma attached. They feel like there's a stigma attached to it, particularly being male you should deal with it.… but I don't know if it's something that, you know, it could just be stuff that is not spoken about but they're [men in the community] dealing with certain things and they just don't see another way out of it.

4.2 Secrecy and Stigma

Secrecy surrounding the topic of psychosocial disability in the South African Indian Hindu community was a prominent theme that emerged from the data. For most participants, regardless of their individual thoughts about- or understandings of- psychosocial disability, their family member's psychosocial disability is handled and experienced as a private, and even secret, matter (kept within the intimate family and/or close friend setting). This is linked to a fear of community's, and even extended family's ignorance, misunderstanding, judgement, as well as potential stigma.

Various participants spoke about how psychosocial disability is not a topic of discussion in the South African Indian Hindu community, giving them the impression that

this issue remains a secret one. Participant B said, *"With the Indian community I don't think mental illness is going to be a topic to talk about openly. But I wish I could open my mouth."*

And participant D said:

Like personally, if I had to, if I feel like I'm, I need to see a psychologist for example. I mean I, I have not seen one, but if perhaps at a later stage in life, I don't think I would tell anybody that I was seeing a psychologist. It's simply because it's topics like this that is not discussed. It is like, for example, in a typical Indian household, you will never sit down and have the talk about contraception you would never because it's something that is never discussed. There are certain things that is never discussed and I think that mental illness, quite possibly, maybe one of those things that is just not talked about.

Participants communicated an active ignoring of the presence of psychosocial disability in extended family settings. When speaking about her sister's eating disorder, participant F said,

I would say like they [extended family] had a suspicion because there wasa time when my sister was studying in Durban and she was staying with my dad's oldest brother. And obviously her eating habits differed majorly from their eating habits. But they never really spoke about it.

Participant A echoed this sentiment:

...so there's some cousins who are concerned, that want him to get better and they're that they kind of obviously emotionally support him. And then there's just some cousins that are ...They, they get along with us, but they don't really pay attention to what these issues are or in that kind of aspect of his life. It's just a thing of like being polite and getting along when, you know, when we are together kind of thing.

Participant F, in relation to her parents eventually having to intervene in her sister's eating disorder, linked the general avoidance of the discussion about psychosocial disability in the community to stigma,

...with Indian communities, you know like these type of thingsare quite taboo, you know, they're not like speaking about it. They're not like addressing it. So they didn't quite address it until so like I said, it got severe to the extent of if she continued, we were going to have to take her to hospital because it was getting that bad.

Similarly, when referring to an encounter with a close friend, participant D said:

But her dad a couple of years ago also was diagnosed with a mental illness. And one of the things that she said to me at that time when she told me about it was, 'please don't tell anybody'. So I'm thinking perhaps if you're looking at these two cases it is something that is not spoken about. Perhaps there is a stigma attached to it. Perhaps people feel that they would be viewed differently...

And participant E reflected,

So I think there is a fair amount of stigma… obviously for myself, I haven't, I mean people as I said also don't speak about it so openly. But definitely there is there, there is some stigma attached to it but more, but more so, and I thinkthat's just from, from the lack of understanding…

Stigma, a key component of the secrecy surrounding psychosocial disability, was seen by all participants as being underlined by a general lack of exposure to-, understanding of-, and ignorance surrounding psychosocial disability by people in the community. When speaking about possible ignorance and lack of understanding in the South African Hindu community, participant D reflected on my use of the phrase, "psychosocial disability" in the study versus using "mental illness". Participant D said:

I didn't hear the words like 'social disability' before. It's the first time I've heard it. But it makes more sense than saying mental illness because mental illness is perceived very negatively. I think it is less harsh than mental illness because mental illness, you, I don't know. But, but personally you would associate with somebody being confined to an institution as opposed to being a normal functioning member of society that perhaps doesn't function on the same level as every other member of society does.

Participant E further elaborated regarding the community's limited understanding of psychosocial disability:

Well, for me, I think there's still a lot of work to do in terms of the, the Indian community and obviously the understanding and the awareness. And I think not just with the Indian community, but people at large when it comes to understanding psychosocial disabilities, etc. …some people are still very close minded about it. Some are more open minded. It just depends again on many factors of, of their lives and what their experience is with obviously, with anyone suffering from, from these conditions for sure. So it, it is

definitely a topic that needs to be educated about for the communities at large; and, and if you think about faith and also cultural beliefs… I think people also sometimes turn to that more even then, actually seeking help from professionals and, and thatmight be their way of dealing with, with what's happening. And that's also from, from ignorance of, of, of the condition or yeah.

Participant D asserted that ignorance and misunderstanding regarding psychosocial disability may be linked to lack of exposure to psychosocial disability in particular communities. She spoke about returning to live in her small hometown and how psychosocial disability may be more talked about in larger communities or different environments,

You see the, the, the problem with me is that, after I finished school, I lived away from here for 10 years. And so for the 10 years that I wasn't here my world view changed because I lived in various places. So then we're coming back here. Now, now that you're asking me the question, it is something I never thought about, but nobody talks about mental illness…in this community.

Similarly, participant F said, *"Like I said, and I don't say I don't know how to explain it, but like in other communities, I can see there is a change slowly starting to happen, although it'sreally slow and not progressing much…".* When asked to elaborate, participant F made reference to the difference in exposure and knowledge of psychosocial disability in urban versus rural areas by saying, *"I don't want to sound really mean, but like most established areas, you know what I mean? So for example, like Joburg and like certain aspects that are suburban."*

Other participants expressed their concerns regarding the consequences of this ignorance surrounding psychosocial disability, such as judgement and fear from others towards themselves and their family member with the psychosocial disability. Participant B said:

So I'm gonna tell the next person, 'You know what my uncle's got a mental illness', they're not gonna understand the depth of what I'm telling them. You know it's, it's, it's not an easy topic to discuss as well on the same context, you cannot just go and let it out to everybody because initially everyone's mindsets are not the same. You know, you'll get your judgmental people.;…because people will be, generally be afraid to be near him[?] and you

know, interact with him, and that's not the life I wanted for him. I wanted him to make friends andhave friends.

Similarly, Participant F revealed her parents' concerns regarding addressing her sister's eating disorder with extended family:

Like I was saying, she [her sister] was staying with my uncle and stuff.you could obviously see something was wrong, but our parents did not want to address it also cause the fear of judgment of family members. What are they gonna say? You know, because you know how Indian communities are like. They're very judgmental people, even if it's your own family, they're gonna be like, 'Why aren't you taking care of your child?', 'Why are you letting her go through this', even though they [her parents] have no control over it.

Participant B spoke to how misunderstanding can also come in the form of pity:

You get your people who feel sorry for them, and I don't think the person with mental illness will appreciate people hovering all over them and giving them sympathy… I don't think it helps the process. I don't think so because then you're gonna get more pity out of it than actuallyfeelings out of it.

This mindset has led to a strong hesitance from participants and participants' families to share their experiences with psychosocial disability publicly, preferring to speak about it only within their immediate family and friends, reinforcing the secrecy and stigma of psychosocial disability. When referring to her uncle, participant B said:

Nobody but the immediate family knows about his sickness.; Not, not anybody knows that he does have a mental illness because I didn't think it was right for me to, you know, let people know about it. I think we are family, we wanted tokeep it to ourselves. Because he's not a threat out there to anybody; We, we have very judgemental people around us, especially in the Indian communityas well and I feel that people will be judgmental and it's best left with the family.

Similarly, participant E regarding her daughter's diagnosis, said:

So I haven't, I haven't spoken to any other family members. Honestly. It's just been my parents. And that's purely because they're the closest ones to her, yeah. So I haven't shared that with, with anyone else in the family, …it's not stuff that we didn't share because it's something to hide or whatever. But I think the right now is, is a sensitive time for her and and, and I just, we decided that it's obviously the people that are closest to her that support

her would, would, would need to know, yeah…who she shares with and who she wants support from. And then obviously, I've reached out to my pastor just for, you know, some advice.

Participant A said about her immediate community *"…in terms of like neighbours and things, like they don't really know. Like they know that my brother like is kind of like the black sheep, but they don't understand why."* Participant A went on to speak about her brother's concerns in sharing details of his diagnosis and experience with extended family,

…he [participant A's brother] wanted to keep it [his psychosocial disability status] very private from the extended family. So like there was no extended family supports because he didn't want anyone knowing; He didn't want the extended family knowing when he went to rehab because therewere some family members that he felt didn't care enough.

Like the other participants when asked about who knew about her aunt's psychosocial disability, Participant D spoke about immediate family and close friends' involvement. But instead of her focus being on fear of outside judgement, she spoke more from the perspective of individuals in her close-knit community having more exposure to psychosocial disability, and thus more understanding and less judgement. Participant D said:

… I know lots of people that have people in their families with mental impairments or some sort of disability. So everybody, there's no negativity surrounding it. There is no negativity like people are not judgemental or anything like that. We are quite a small community as well, so. Yeah,people generally do know each other, and we know what's going on, but I, I don't want to speak for the entire community…They all know my aunt, so they like are very understanding….there's no judgment orthere's no, like, oh, they're getting irritated and nothing of that sort. Nobody. Nobody that I know of, ever gets irritated or frustrated.

4.3 Family experience

Family plays a major role in the care and support of individuals with psychosocial disability, especially in the context of the South African Indian Hindu community where family connection and responsibility is one of the core values (Archary & Landman, 2022; Radhakrishnan, 2005; Yusuf et al., 2009). The study's focus on the perspectives of family members of individuals with a psychosocial disability highlighted two main aspects of their

experience. Firstly, the study highlighted the responsibility of care that family members take on in their engagement with the individual with the psychosocial disability. And secondly, it highlighted the nuanced emotional response of family members towards the individual with a psychosocial disability,which moves between empathy, understanding and nurturance, to feelings of frustration, resentment, and impatience.

4.3.1 Family responsibility

All the participants felt that ultimately the responsibility of care of the individual with the psychosocial disability falls onto family members. Participants spoke at length about how accommodating the needs of the individual with the psychosocial disability required gentle navigation and full effort, understanding, and negotiation from all family members involved.

Participant B spoke about how family involvement is crucial to the wellbeing of the individual with a psychosocial disability and about how their family has a responsibility to provide support and understanding. She said:

Clearly they [individuals with psychosocial disabilities] don't have a mind to make decisions. So in that instance that's when the family steps in." In the context of family members providing care she went on to say*, " ...people that have mental illness should not be shut down from society or from life itself. They also have a life to live. And given the right TLC [Tender, Love and Care]." And, "You know, for them it can, they can overcome it as well.*

Participant B also spoke with great emotion about her experience of visiting her uncle while he was institutionalised and the lack of family support she saw at the facility:

...[I] used to go visit him, it's the saddest thing ever to go to the hospital, because you find the young, the old, the middle-aged, there's no family visiting them, so in terms of that its very hurtful and heart breaking, and I wish I had a part in that to go out and tell the people, you know, what your family member should mean something to you.

Other participants recounted their experiences of their family member with a psychosocial disability being reliant on them and the family system. Participant D said, *"My dad looks after them. Yeah. My dad takes care of his siblings.";*

"... that's also part of the reason why I ended up staying around to help himand my mom because he wasn't managing on his own." Similarly, when speaking about her daughter

participant E said,

Yeah, but she just needs some help, obviously, to, to get her through this this time.; And if there's something that upsets her or she was anxious about something, then obviously as a family, we would, we would regroup and we wouldn't, if she, she couldn't be around people for too long, then she just wanted to get back home.

Participant C spoke about how when her mother had 'episodes' and could not function, her close extended family would step in, *"...but extended family played a major part in bringing normalcy to that. So I know aunties and uncles and everybody just stepped in and did what needed to."*

The ability of close family members to be a support structure and take on the responsibility of care was not a naturally occurring practice but rather one that took time, patience, and communication. Participant E spoke about navigating the care of her daughter (diagnosed with high functioning depression) and her other two children. She said:

...each one of them are very different, but also dealing with, with that and and, and changing family activities to also suit that [her daughter's disability], sometimes the understanding was not there because she wasn't verbal about, 'I'm feeling anxious today. I don't want to do this.' So we wouldn't understand when she would just get upset or angry or whatever...

She went on to speak about how gaining that nurturance and understanding for her daughter was a gradual process for the whole family:

Obviously, when they were younger, I think the understanding wasn't there. Maybe her older sister that's 24, 23 now, understand, understood her better than I mean, her brother's younger than her he's 17. And obviously they didn't understand they just thought, 'oh, she was obviously…' he especially thought, 'Oh, she's just a moody teenager', you know...But understanding now is definitely there because we've had the conversation of where we are, you know, in terms of her and have made the diagnosis and what we all haveto do in order to help her through this time...

Participant B recounted the difficult times she had had with her uncle, as a result of

his disability, when he first moved in with her and her family, and having to explain to her children what this condition was like for him so that there could be an understanding and a shift in their mind set:

...being a close family, we sat and we had a good chat about it. And my children understood that it was something that just triggered his mind. He didn't ask for it to happen. It just happened. With that in mind, yeah, we overcame a lot and I think that is why our bond with my uncle is so great, because we've been through hell and back with him, so to speak.

Participant C spoke about how as a child, her family had become very familiar with her mother's disability over time and just stepped right into action whenever she had an episode:

...she put the family in the situation where, you know, she was unable to care for us ...when she had those, I don't even know what to call it let's just call it 'episodes', then everybody just knew this is what it is. We understood that was something that was going on and people just stepped in to make changes to suit her.

This dynamic has continued in participant C's adult life as her and her family continue to accommodate her mother's needs. She gave an example of when her brother needed to trim a tree at his property where her mother was also living:

...we always try to balance like how important, is this in our lives, compared to what she [her mother] would be going through. So in that way you know, if a decision is being made about something, then what should have just been my brother and sister in law's decision about their own home now becomes a family decision because we have to place her [her mother] interest first.

4.3.2 Family emotional response

Family members bring compassion and understanding into their interactions with individuals with psychosocial disability. However, the nature of the various conditions, the duration of conditions, and the burden of care can be very overwhelming, leading to complicated feelings on the side of the family members. Participants expressed a range of feelings when speaking about their experiences with their family member with the psychosocial disability.

When asked about her family's everyday experience, participant A spoke about her mother's complex feelings surrounding living with her brother:

Um, in terms of like my mom, uh, she was always like very supportive. She was always doing whatever she could to make sure that he was safe and stuff. It's just in like, at that time, understandably, she was like doing everything she could, but it's kind of progressed to a thing where I, I feel like my brother got a little too comfortable with having things sorted for him. So in recent years,…it went from a thing of my mom doing it out of like love and support because she wanted him to get better to it being a thing where she feels like she has no choice because there's like no option for him to do anything otherwise;

...she went from a place of being very empathetic and I feel like that's kind of draining as time goes on because it's getting like harder to maintain that level of care.

Participant A then moved on to speaking about her own experiences:

…it feels like I'm the oldest sibling, if that makes sense. Like it just feels like I have to take over the responsibilities of the house financially at, to work while studying, um, chore-wise, all of that stuff. So it's like, I think it's also kind of becoming a bit of a resentful thing. So we all just, I'm trying to be patient with him about it and like try to encourage him to, you know, work on stuff and it's happening, but it's happening at a very slow pace. But it, but it is happening.

While both her mother and participant A juggle feelings of compassion and frustration, there is a sense of extended family, who have some vague understanding of his diagnosis, who feel very little for his situation: *"…they kind of like run out of empathy at like a certain level, but like very, they have very limited consideration for him if I can say that."*

When asked the same question, participant D spoke to the stress related to long-term caregiving of an individual with a psychosocial disability:

It's stressful. We went through a very bad patch with my Gran [who was also suspected of having a psychosocial disability], where let's just like you know it, it takes its toll on everybody because we end up arguing as well about certain things and it's not easy because, as I say, my dad looks after his siblings.

In this same vein, when speaking about her aunt, participant D expressed the effects on her father of being a long-term caregiver,

It has taken its toll it has and I see lately he's getting a bit more frustrated with her. In terms of lets you know, she's constantly asking himwhere he is, what time he's going to come home and you know, like that kind of stuff.

When reflecting on her experiences, Participant C spoke about not understanding the gravity of her mother's eccentric behaviours until much later in life:

... in retrospect, as we grew up and we spoke about these incidents and laughed about it and teased her about it, we kind of figured, okay, there was something wrong, but at the moment, you know, living in it, it, it never occurred to us that something is really wrong at that point. But of course, as you grow and then the incidents repeat itself, you realise, okay, this is something that's not quite the normal scene.

She spoke a little bit around how she and the family feel about her mother's psychosocial disability presently:

...I think knowing that it will pass [the episode]….we find coping strategies until it does pass, and of course it is stressful for everyone at the time and then being able to laugh about it later on kind of makes it okay. I know it doesn't make it okay, for her but she's okay with being teased about it later on…, I think those things kind of make it a little more bearable, but of course. It's little anxiety. It still induces anxiety for everyone.

Participant F also spoke about anxiety, but from the perspective of wanting to help and be there for her family member with the psychosocial disability. Participant F expressed how difficult it was to see her sister suffering through her eating disorder that she refused to admit that she had. Participant F said, *"…it was tough, especially given she as my older sister. And you're like you seen them struggle and you can't really do much to help because you yourself don't quite understand what's happening yet."* She also spoke about the conflict in her family as a result of her sister's inability to acknowledge her behaviour and her condition:

But what I come to notice is that she tends to, how can I say like fight ohh make my, my dad, the villain in everything. Even though that's not the case… not so much with my

mom, but that could be because my mom would take her side. But now recently she's come to realize that they've been several situations where my sister wasn't around. And my dad was actually, right.

Participant E expressed anxiety regarding her daughter navigating the diagnosis while studying in Cape Town for eight months of the year. She said:

...being a mom and having away from home, the constant worry and the concern is there and, and, and I think I've become a little bit more protective over her in terms of checking in and making sure she's okay and yeah, so I think I think my suffocates are a little bit right now because of, of how often I'm like checking in, "are you OK?" And I think all our conversations are really very around you know. "How are you feeling?", "Did you take your meds?" Cause I have to call her every morning to wake her up because she battles to wake up. So yeah, so I think for me it's now more to worry, the concern around her not being at home and me not able to help her?

Most participants spoke about the fluctuating nature of psychosocial disability, in that there are periods where their relationship and engagement with their family member has been more harmonious and stable, and there are periods where it has been extremely difficult and at times even dangerous for both them and/or their family member. Participant B, specifically, spoke about the very challenging time they had with her uncle when he first came to live with her family and the complicated feelings surrounding this encounter:

And, and for my kids, they were traumatised, they, they really because we had to stay at our neighbour's house for a while until the police came and took my uncle because he was being very violent and, you know, in the sense of wanting to do something or more kill my husband. So that traumatised my kids a lot.

She spoke about the anger she felt towards him for putting her family in that position and the hesitance she had about him returning to live in her home. Ultimately, she felt that regardless of his actions it was her responsibility as a family member to look out for him and she spoke to the strength of their current relationship:

With that in mind, yeah, we overcame a lot and I think that is why our bond with my

uncle is so great, because we've been through hell and back with him, so to speak. "Overall, you know, beside the [inaudible] he has been overall a very good person. Because we've actually got on like a house on fire. I mean I'm very close to my uncle. And I took him like a second dad for my, and we've created a bond where we understand each other. So if you know him then only you would understand that you wouldn't even say he's got a problem, because he carries himself so well.

The above explored the South African Indian Hindu community's understanding of- and experience with- psychosocial disability. In terms of understanding, participants spoke about two perspectives regarding psychosocial disability that are engaged with differently between generations in the community. The first was a cultural understanding that seems to be aligned with traditional values regarding gender, religion, and culture that position psychosocial disability as a problem that requires a permanent, external solution. The second is a biomedical understanding that aligns with 'modern' conceptualisations of psychiatric illness that require a nuanced approach to navigating.

In terms of experience, participants spoke about the responsibility that families of individuals with psychosocial disability have in the care of their family members. They referred to their own experiences of various family members playing prominent roles in monitoring their family members with a psychosocial disability and providing - emotional and material support. Understanding psychosocial disability and how it may manifest for an individual was highlighted as an essential tenant in being able to care appropriately for an individual with a psychosocial disability. Participants also discussed the spectrum of emotions involved in caring for an individual with a psychosocial disability. They commented on the difficulty they experienced holding onto feelings of compassion and empathy when confronted with long or demanding periods of caring that resulted in feelings of resentment, frustration, anger, fatigue, and hurt on the side of the caregivers.

Ultimately, participants felt that negative cultural beliefs and a lack of exposure to psychosocial disability, as well as a lack ofunderstanding of psychosocial disability, translates into individuals with psychosocial disability being largely stigmatised in the South African Indian Hindu community.

Additionally, it appears that this mindset causes family members of individuals with psychosocial disability and the individuals themselves to continuously understand and experience psychosocial disability as secret or a private matter, only discussed and dealt with within the close family and friend setting, increasing the caregiver burden and fear of

community judgement, shaming, and exclusion.

CHAPTER 5: DISCUSSION

This study sought to explore how the South African Indian Hindu community navigates, relates to, and makes sense of psychosocial disability. As explored previously, the South African Indian Hindu community has tried to preserve their identity as a diaspora community in South Africa by maintaining their cultural, social, and familial connection to their country of origin (Archary & Landman, 2022; Radhakrishnan, 2005). Thus, the South African Indian Hindu community's rules of engagement, norms, boundaries, communication patterns, and understanding have been shaped by the central tenants of the Indian community (Chadda & Deb, 2013; Daya, 2017). These tenants are family connection and interdependence, religiosity, and a hierarchical system of age (where elders are respected and ranked above all others) and gender (where a patriarchal structure ascribes specific roles and responsibilities to each gender) (Chadda & Deb, 2013; Daya, 2017). This social structure was reflected in participants' portrayals of the South African Indian Hindu community and in their engagement with psychosocial disability. The presence of this social structure in the South African Indian Hindu community adds to existing literature that has emphasised the major impact that cultural values and understandings have on how psychosocial disability is perceived and engaged with in different cultural communities (Ally& Laher, 2008; Bulbulia & Laher, 2013; Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). Cultural understandings, beliefs, and values have been highlighted by participants in this study as having a significant impact on the community's acquisition of knowledge, disclosure, treatment seeking, family and caregiving behaviours, beliefs, and consequences associated with psychosocial disability.

5.1 Defining psychosocial disability

Previous studies conducted on the conceptualisations of psychosocial disability in the South African Indian Hindu community have outlined Hinduism's holistic understanding of an individual's wellbeing and its relation to psychosocial disability (Ally & Laher, 2008; Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). These studies discussed how an imbalance in the mind, body, and soul of an individual is seen as resulting in a mental, physical, or spiritual illness (Ally & Laher, 2008; Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). In the current research study, the cultural understanding of psychosocial disability was characterised similarly and further explored as a consequence of personal or familial transgressions or external negative forces enacted upon an individual (Laher, 2014; Padayachee & Laher, 2014). Previous studies also highlighted the

tendency of mental illnesses and spiritual illnesses to manifest similarly and reflected on the capacity of individuals, and to some extent mental health practitioners, to acknowledge the overlap between mental illness and spiritual illness (Ally & Laher, 2008; Engelbrecht & Kasiram, 2012; Laher, 2014; Padayachee & Laher, 2014). However, in this research study participants made a clear distinction between the biomedical understanding and cultural understanding of psychosocial disability (mental illness versus spiritual illness) and the resulting beliefs and potential behaviours associated with each definition with very limited discussion regarding the possible interaction between the two understandings.

Participants not only emphasised the differences between these two understandings but also presented them as opposing. Cultural understandings of psychosocial disability were seen as largely negative, restrictive, secretive and labelling, while a Western biomedical understanding of psychosocial disability was referred to as 'modern' and was seen as synonymous with a progressive mindset. This dichotomous understanding of psychosocial disability in the South African Indian Hindu community was further linked by participants to generational differences. The cultural understanding of psychosocial disability was seen as representative of a traditional mindset, rigidity, and a lack of education regarding psychosocial disability associated with the older generation in the community. The Western understanding aligned more with the beliefs of the younger generation in the community and was related to their increased exposure to- and education surrounding psychosocial disability and more prominent western influences in schooling systems, tertiary institutions, and social media.

Participants who were considered middle aged (roughly between the ages of 37 and 48)engaged with this dichotomous understanding of psychosocial disability in a more integrated way compared to participants on either side of this age range. They placed value on maintaining one's connection to cultural beliefs and spiritual understandings but understood psychosocial disability and its associated management methods from a more biomedical perspective. Their dual mindset was attributed to social media, exposure and discussions in occupational spaces, and experiences with their children and younger family members.

However, regardless of their more dual mindset about psychosocial disability, ultimately their understanding with psychosocial disability in the South African Indian Hindu community mirrored the dichotomous understanding explored above. This distinction

between definitions of psychosocial disability provides insight into how psychosocial disability may be understood in the Indian Hindu community in contemporary South Africa. However, it is also important to understand if and how these understandings translate into everyday interactions with psychosocial disability (Bulbulia & Laher, 2013; Dockery et al., 2015; Engelbrecht & Kasiram, 2012; Padayachee & Laher, 2014). While two distinct definitions were identified, the majority of participants highlightedone of them, namely the cultural understanding of psychosocial disability, as having a more significant impact on the South African Indian Hindu community's lived experience and everyday engagement with psychosocial disability, regardless of individual modern, biomedical views and beliefs about psychosocial disability.

5.2 Family experiences with psychosocial disability

Participants experiences with their family member with a psychosocial disability was explored. They also discussed the prominence of the cultural understanding of psychosocial disability within the South African Indian Hindu community and the negative impact of this understanding on both the individual with the psychosocial disability and the family members of the individual.

All participants referred to the integral role and responsibility that the family unit has in acknowledging, supporting, and caring for an individual with a psychosocial disability. The findings further emphasised the impact of psychosocial disability on the family system, namely how one individual's psychosocial disability affects the entire family with regards to a shift in family expectations of that family member and a change in household engagement, roles, and responsibilities (Chadda & Deb, 2013; Daya, 2017; Ntsayagae et al., 2019).

Participants in this study also spoke about the complex emotional, physical and financial struggles that they and their family have experienced in their everyday engagement with theirfamily member's psychosocial disability. These struggles mirrored multiple studies that haveexplored the difficulties associated with the care and support of individuals with psychosocialdisabilities and the negative and longstanding impact that caring can have on the caregiver (e.g., Jonker & Greeff, 2009; Rose et al., 2002).

In terms of financial and physical difficulties, participant responses in this research study echoed previous studies discussing the compromises that family members of individuals with a psychosocial disability have to make in order to provide consistent support. Participants reported the negative impact of their family member's psychosocial disability on

their own physical and mental well-being, as well as the adjustments they have had to make regarding their lifestyle, place of residence, and engagement with others. They also spoke aboutthe difficulties associated with having an individual being completely reliant on them and thus unable to independently meet their own physical and financial needs (Rose et al., 2002;Schierenbeck et al., 2013; Yerriah et al., 2022; Yusuf et al., 2009).

In terms of emotional challenges, while participants approached their family member's psychosocial disability with empathy and care they had difficulty maintaining this understanding for their family member over long stretches of caring. These stretches usually involved fluctuating periods of stability and resulted in feelings of anger, frustration, resentment, and hurt towards that family member (Schierenbeck et al., 2013; Yerriah et al., 2022). Participants also expressed guilt around not being able to fully understand what that family member is experiencing. As well as having constant worries regarding their family member's wellbeing and the potential for their family member's psychosocial disability to regress (Rose et al., 2002). Furthermore, family members expressed concerns and fear regarding the lack of patience and empathy that extended family or outside individuals have towards their family member with the psychosocial disability. This was also found to be the case in existing research (Dockery et al., 2015; Engelbrecht & Kasiram, 2012; Rose et al., 2002; Schierenbeck et al., 2013). However, participants also expressed that over time they have been able to learn more about their family member and their illness and develop coping mechanisms to help manage their own stress and anxiety related to the care and management of their family member (Mabunda et al., 2022; Petersen & Monnapula-Mazabane, 2021).

Participants further reflected on their experiences with psychosocial disability specifically within the South African Indian Hindu community and highlighted the major impact of cultural understandings of psychosocial disability. Negative cultural conceptualisations of psychosocial disability across cultural groups have been identified as creating a narrative around psychosocial disability that is invalidating and minimising (Dockery et al., 2015; Engelbrecht & Kasiram, 2012). These beliefs and misconceptions around psychosocial disability are often fuelled by a lack of education and awareness about psychosocial disability (Dockery et al., 2015; Engelbrecht & Kasiram, 2012; Rose et al., 2002; Schierenbeck et al., 2013). These beliefs add a layer of difficulty to individuals' experiences with psychosocial disability and act as a barrier to care, understanding, and support within different cultural communities (Dockery et al., 2015; Engelbrecht & Kasiram, 2012; Rose etal., 2002; Schierenbeck et al., 2013).

Similarly, in this study the cultural understanding of psychosocial disability within the South African Indian Hindu community was seen by participants as maintaining of harmful and negative beliefs. The cultural understanding of psychosocial disability positions psychosocial disability as an insulated issue from the community and outsources the responsibility of the psychosocial disability onto the individual and the individual's family. Participants felt that this way of engaging with psychosocial disability was seen as perpetuating of a cycle of shame, secrecy, and stigma within the community. In turn, these negative beliefs were seen as affecting the disclosure and treatment seeking behaviours of individuals with psychosocial disabilities as well as the beliefs, behaviours, and experiences of other family members and caregivers.

The topic of psychosocial disability in the South African Indian Hindu community was experienced by participants as a private matter. The active ignoring, overlooking, misunderstanding, or dismissal of signs and behaviours related to psychosocial disability by extended family and within the community was seen as discouraging of an open discussion about psychosocial disability. Participants relayed being able to disclose their family member's diagnosis and their related challenges within close and trusted friend and family settings. However, disclosure was based on the premise that these individuals would not further these discussions into the external community (Mabunda et al., 2022; Petersen & Monnapula-Mazabane, 2021; Rose et al., 2002).

The South African Indian Hindu community's reluctance to engage with psychosocial disability was further linked by participants to stigma based on a lack of education and exposure surrounding psychosocial disability. While some participants expressed a desire for the community to speak more openly about psychosocial disability they also spoke to their lived experiences and fears regarding the negative treatment and belittling of their family members with a psychosocial disability and themselves by other members of the community (Yerriah et al., 2022). Additionally, they spoke to their fears around how public disclosure may result in a negative narrative being built around the family member with the psychosocial disability.Family members attempted to preserve the dignity of that individual by refraining from public discussions about psychosocial disability, as also seen inthe existing literature (Dockery et al., 2015; Engelbrecht & Kasiram, 2012; Rose et al., 2002; Schierenbeck et al., 2013).

Community engagement with psychosocial disability based on a lack of education and negative cultural narratives puts pressure on individuals with a psychosocial disability and

their family members to navigate psychosocial disability in a covert manner that limits their ability to ask for guidance and help within their community (Addo et al., 2018; Dockery et al., 2015; Engelbrecht & Kasiram, 2012). It also leaves individuals with feelings of shame, guilt, fear, and helplessness surrounding their connection to and experiences with psychosocial disability, despite their own individual and differing beliefs regarding psychosocial disability (Jonker & Greeff, 2009; Padayachee & Laher, 2014; Rose et al., 2002).

5.3 Implications of a cultural understanding of psychosocial disability in the South African Indian Hindu community

In this study, cultural beliefs and understandings about psychosocial disability in the South African Indian Hindu community have been identified as having a major influence on how the community defines and experiences psychosocial disability, despite individual beliefs that align with a Westernised understanding. The prominence placed on cultural values and beliefs was linked to the historical need of the Indian community in South Africa to maintain their connection to their home country. However, it has also highlighted the absence of cultural knowledges outside of the community. The absence appears to perpetuate a reluctance in the South African Indian Hindu community to engage with Western understandings of psychosocial disability as a larger community. This has implications for the South African health care system and its ability to provide relevant care to different cultural communities as it engages with psychosocial disability from a predominately Western understanding (Bulbulia & Laher, 2013; Petersen & Lund, 2011; Schierenbeck et al., 2013).

The reluctance of the South African Indian Hindu community as a larger community to engage with a Western understanding of psychosocial disability can be linked to literature that has addressed the consequences of navigating psychosocial disability in the absence of cultural understandings, i.e., from a predominantly Western perspective. Studies conducted in South Africa have looked at how addressing psychosocial disability from within an exclusively Western understanding frames health as individualised (Bulbulia & Laher, 2013; Engelbrecht & Kasiram, 2012; Padayachee & Laher, 2014). This understanding of health emphasises the individual impact of psychosocial disability and personal responsibility

that a person has in the management of their health, which fails to incorporate communal and spiritual understandings and overlooks their impact on a community (Padayachee & Laher, 2014). This way of thinking also has the potential for pathologising behaviours, beliefs, and patterns of relational engagement that are considered quite culturally appropriate in collectivist societies (such as the South African Indian Hindu community). Furthermore, this thinking result in incorrect assessment, diagnosis, or treatment of individuals with a psychosocial disability and in the deepening of fear, confusion, and stigma surrounding psychosocial disability in different cultural communities in South Africa (Dockery et al., 2015; Johnston, 2015; Padayachee & Laher, 2014).

In the South African Indian Hindu community, participants attributed the stigma, negative cultural narratives, and secrecy surrounding psychosocial disability to a lack of knowledge (i.e., a lack of education) about psychosocial disability, particularly with regards to the older generation. A lack of knowledge around psychosocial disability is a contributing factor to stigma and misinformation andcan be linked to a lack of resources or avenues of access to information about psychosocial disability (e.g., a lack of community-based programmes, clinics, sources of technology, mental health care professionals in the community etc.) (Dockery et al., 2015; Hendricks et al., 2014; Lund et al., 2012; Schrienbeck et al., 2013). However, in this context a 'lack of knowledge' appears to be less about limited resources to education about psychosocial disability but rather fueled by a reluctance of the South African Indian Hindu community to engage with this information. A Western paradigm does not allow space for a collectivist mindset regarding psychosocial disability (Padayachee & Laher, 2012). Thus, regarding the current study, the South African Indian Hindu community may come from the perspective that an acceptance or engagement with a more Westernised understanding of psychosocial disability symbolises a relinquishing of cultural values and beliefs which are central to the South African Indian Hindu community's identity (Padayachee & Laher, 2012). This seems particularly relevant as in this study, the cultural and Western understandings of psychosocial disability have been presented as not only different but as opposing.

Additionally, a Westernised understanding of psychosocial disability may be interpreted by the South African Indian Hindu community as a threat to their family structure. As touched on earlier, participants reflected on how the psychosocial disability of an individual shifts the familial structure in terms of roles, expectations, and responsibilities, which in the South African Indian Hindu community are based on beliefs about gender and

age (Chadda & Deb, 2013; Daya, 2017). The expectation that this community would alter these familial roles without the mental health care system in South Africa having an understanding of the significance of these roles and ways to address these changes in the family system and in the community further highlights the difficulty the community has with engaging in a more individualised perspective on health (Padayachee & Laher, 2012).

Individuals from different non-Western communities in South Africa have reported seeking guidance and treatment from Western medical settings that underplay the importance of cultural values and beliefs regarding psychosocial disability (Padayachee & Laher, 2014). Individuals in these various studies recounted very negative experiences in these settings and felt underrepresented, misunderstood, and dismissed, which created an environment that was seen as irrelevant, inaccessible, and unsafe (Ally & Laher, 2008; Bulbulia & Laher, 2013; Engelbrecht & Kasiram, 2012; Padayachee & Laher, 2014). Excluding cultural understandings from the discussion around psychosocial disability in 'modern' medical settings positions cultural understandings as unimportant, archaic, and as not having a place in modern day medicine (Venn, 2010). Ultimately, engaging with psychosocial disability from one perspective limits the ways in which individuals can make sense of the often-overwhelming concept of psychosocial disability. Additionally, it further discourages individuals from seeking guidance and treatment in Western medical settings (Padayachee & Laher, 2014; Venn, 2010).

Exploring the cultural beliefs and understandings of different cultural communities, and ascertaining their impact, allows the mental health care system to approach psychosocial disability with a dual understanding (acknowledging the importance of both cultural and Western ways of engagement with psychosocial disability). A dual understanding promotes a more relevant, inclusive, and holistic approach to psychosocial disability (Johnston, 2015; Padayachee & Laher, 2014; Petersen & Lund, 2011; Laher, 2014). Addressing psychosocial disability from a dual perspective also makes the concept of psychosocial disability, and its associated treatment, more accessible and acceptable to individuals from different communities in South Africa. Engagement with psychosocial disability from a dual perspectivehelps to create an environment that lessens the stigma and the burden of care placed on family members of individuals with psychosocial disability (Dockery et al., 2015; Engelbrecht & Kasiram et al., 2013; Yerriah et al., 2022; Yusuf et al., 2009).

A further implication of acknowledging the importance and impact of cultural understandings of psychosocial disability in medical settings that are characterised as Western, is the possibility of integration. Integration refers to using Western and cultural understandings of psychosocial disability not only in the conceptualisation of psychosocial disability but also in the management of psychosocial disability (Bhagwan, 2012; Laher, 2014; Venn, 2010). In this study, the cultural understanding in the South African Indian Hindu community of psychosocial disability was referred to as largely negative and alluded to as outdated. However, there is existing literature that acknowledges the dynamic approach of Hinduism, as a philosophy of life, to mental health and wellness (Lal & Vahed, 2013; Padayachee & Laher, 2014). This literature also discusses the potential for a more integrated or collaborative approach to the management of psychosocial disability, where cultural knowledges are applied in conjunction with a biomedical understanding of psychosocial disability (Bhagwan, 2012; Laher, 2014; Venn, 2010). It explores how traditional interventions (such as consultations with traditional healers, prayer, chanting, guided meditation, and reading of scripture), that are aimed at addressing imbalances and promoting an individual's overall health and well-being, provide sustainable skills and encourage principles of self-reflection, introspection, emotional regulation, and mindfulness (Bhagwan, 2012; Laher, 2014; Venn, 2010). These principles are very much in line with the desired outcomes of current Western counselling and psychosocial interventions (Bhatia et al., 2013; Johnston, 2015; Laher, 2014).

The above has discussed the major impact of cultural conceptualisations of psychosocial disability on the South African Indian Hindu community. The discussion has highlighted the absence of cultural understandings in Western medical settings, and thus the need of the South African Indian Hindu community to preserve community beliefs, practices, and values by positioning themselves as separate and distinct from a Western framework of psychosocial disability. Approaching psychosocial disability from an exclusively Western perspective was seen as restrictive and as leading to experiences of marginalisation and underrepresentation for individuals in non-Western cultural communities, limiting their access and motivation to seek care and support in Western settings. Thus, this study further reflected on the importance of incorporating both cultural and Western understandings of psychosocial disability, as well as promoted an exploration of integrated methods of management of psychosocial disability to provide a more dynamic and relevant approach to mental health care in contemporary South Africa.

CHAPTER SIX: CONCLUSION

This study produced useful insights about the South African Indian Hindu community's engagement with psychosocial disability in contemporary South Africa. The study aimed to define psychosocial disability and to explore the everyday experiences that South African Indian Hindus have with psychosocial disability, particularly in the context of their cultural beliefs and understandings. The study provided distinct perspectives of psychosocial disability which represented the growing tension between traditional and Western influences. The study's interpretation of the dominance of cultural understandings as a means to preserve cultural values and maintain one's identity, provokes introspection and interest about what it means to be Indian, specifically Hindu Indian, in a South African context.

While the study contextualised psychosocial disability within the South African Indian Hindu community, it further highlighted the marginalisation of these cultural knowledges in mainstream medical spaces. This is particularly significant in a culturally diverse country like South Africa with a long history of colonisation and discrimination. The side-lining of cultural knowledges in the South African mental healthcare system feels not only counterintuitive but is unrepresentative of the everyday lived experiences of individuals in SA. This framework appears to translate into ineffective care, increased pressure and a lack of support for individuals with psychosocial disabilities and their families, and ultimately perpetuates a system that disempowers non-Western communities. Moving forward, research directed at the integration of both Western and cultural understandings in mainstream mental health care spaces can assist in creating a more relevant and safer environment for individuals with psychosocial disabilities and their families.

6.1 Limitations

There were limitations to the study, particularly in relation to the sample. The initial inclusion criteria for the study, which required participants to reside in Gauteng with their family members, did not elicit many participants. This initial difficulty in recruiting participants could be interpreted as a reluctance from the South African Indian Hindu community to engage in a discussion about psychosocial disability. However, it was also felt that the initial criterion was restricting and unrepresentative of the Indian family structure,

thus, unfairly disqualifying potential participants. In a Western context, a nuclear family structure is understood by immediate family living in the same household (Chadda & Deb, 2013; Daya, 2017; Padayachee & Laher, 2012). In a non-Western or collectivist context, like the Indian community, key functions of the family system (such as child-rearing, support, care, and decision-making) play out within the broader network of the extended family, existing outside of the household (Chadda & Deb, 2013; Daya, 2017). Thus, the criterion was extended to include individuals who resided anywhere in South Africa and had lived with their family member with a psychosocial disability at one period in time, if not currently.

The inclusion of participants residing outside of the Gauteng province resulted in participant interviews being carried out predominantly online, limiting in-person contact with participants. The online platform created a sense of distance and anonymity which did allow safe and open disclosure of what may have been considered a private topic. However, it was felt that in-person interviews would have allowed for the tracking of non-verbal communication, stronger rapport building, and uninterrupted (no network difficulties) and dynamic engagement that could have elicited richer information and allowed for a deeper exploration of the topic and personal experiences (Archibald et al., 2019).

The limitations extended to the advertisement for the study. The University of the Witwatersrand Hindu Student Society (Wits HSS) was not receptive to advertising this study on their social media platforms despite being contacted several times. This may be representative of the South African Indian Hindu community's engagement with the topic of psychosocial disability as a separate and private matter, the advertising of which feels misplaced in these communal and recreational spaces. Moving forward, it may be helpful to gain the endorsement and support of community and organisation leaders (gatekeepers) individually before advertising (Gill, 2020). This may help other community members feel more comfortable discussing the content and encourage participation (Gill, 2020).

Additionally, the sample was exclusively female. While this may be interpreted as an absence of male interest in this topic, culturally the absence of males may be reflective of the minimisation of males' experiences of- and engagement with psychosocial disability in the South African Indian Hindu community. In other words, males may have not been approached through snowballing to participate or may have felt that psychosocial disability is not a topic that they could engage with safely or without judgement. Male absence in this study highlights the overlooked need for targeted advertisement towards the male

demographic in the Indian community as opposed to letting participant recruitment unfold 'naturally'.

6.2 Future Research and recommendations

This study emphasised the community's impact on the way in which individuals engage with, understand, and interpret psychosocial disability. This study had only six participants. Thus, moving forward more collaborative and community-based frameworks and data collection methods could be used to enable the generation of in-depth content and encourage participation. These methods could take the form of in-person interviews and focus groups which increase engagement and have the potential to elicit richer information. It could also involve the use of Participatory Action Research and Community-Based Participatory Research designs which more actively involve participants and community members in the research process with the goal of a co-creation of knowledge (Vaughn & Jacquez, 2020)

This study used an explorative and interpretative theoretical framework which relies heavily on subjective interpretation and requires the researcher to engage in rigorous reflexivity. More collaborative interventions, as mentioned above, could also assist in recruiting more participants from different age groups, locations and genders, thus diversifying the sample of future studies. A more diverse sample would help in providing a variety of perspectives and experiences that can assist in challenging one's rigid beliefs or biases regarding cultural content or expectations.

The lack of literature regarding contemporary experiences of, and engagement with, psychosocial disability in the South African Indian Hindu community can be extended to many other cultural communities in South Africa. Literature discussed earlier regarding both the negative experiences of non-Western patients in biomedical spaces and regarding the high percentage of individuals from different cultural communities that seek treatment through cultural avenues is a further indication of the importance of cultural understandings in the provision of competent care (Ally & Laher, 2008; Bulbulia & Laher, 2013; Laher, 2014; Padayachee & Laher, 2014). Research of a similar nature to this study, undertaken in different cultural communities, can assist in the training of mental health professionals to be culturally competent in their engagement with their patients, minimising experiences of misunderstanding, misdiagnosis, distress, judgement, and ineffective treatment (Dockery et al., 2015; Johnston, 2015; Padayachee & Laher, 2014). Studies of this nature can also

promote collaboration and shared knowledge between mental health care practitioners and traditional healers, in a movement towards a more integrated mental health care system (Bhatia et al., 2013; Johnston, 2015; Laher, 2014).

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Appendices

Appendix A: Ethics Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: MClin/23/01**
PROJECT TITLE:	How members of the South African Indian Hindu community understand and experience psychosocial disability.
INVESTIGATOR	Habib Sumaya (604200)
SCHOOL/DEPARTMENT OF INVESTIGATOR	SHCD/Psychology
DATE CONSIDERED	16 May 2023
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	Low Risk
EXPIRY DATE	31 December 2025
ISSUE DATE OF CERTIFICATE 23 May 2023	**CHAIRPERSON** _____ (Dr Aline Ferreira Correia)

cc: Dr Clare Harvey (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/we undertake to submit an amendment of the protocol to the Committee.

_____ 08 / 06 / 2023

Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix B: Interview Schedule

INTERVIEW SCHEDULE

Demographic questions:

1. How old are you?
2. What is your relationship to your family member/s with the psychosocial disability?
3. How old is your family member/s with the psychosocial disability?
4. How long have they been diagnosed with the psychosocial disability?
5. How long have you been living with your family member with the psychosocial disability?

Broader questions:

1. What does the term 'psychosocial disability' mean to you?
2. What psychosocial disability does your family member have? Tell me a bit about your experience regarding this, as well as your whole family's experience with them.
3. Did you have any knowledge about psychosocial disability before your family member was diagnosed with a psychosocial disability? Please elaborate
4. What do you perceive to be your family member's experience with the community, in relation to their psychosocial disability? (e.g., how are they treated?/how do they engage?)
5. How does the Hindu community feel about psychosocial disability? (i.e., are there many different feelings/opinions?)
6. What are some of the Hindu community's beliefs about psychosocial disability?
7. Do you think cultural knowledges play a role in understanding and treating psychosocial disability in your community? Tell me a bit about your experiences with this.
8. We have reached the end of the questions on the topic. Is there anything about your experience with psychosocial disability in the South African Indian Hindu community that you feel I have not asked about or that you would like to share?

Debrief questions:

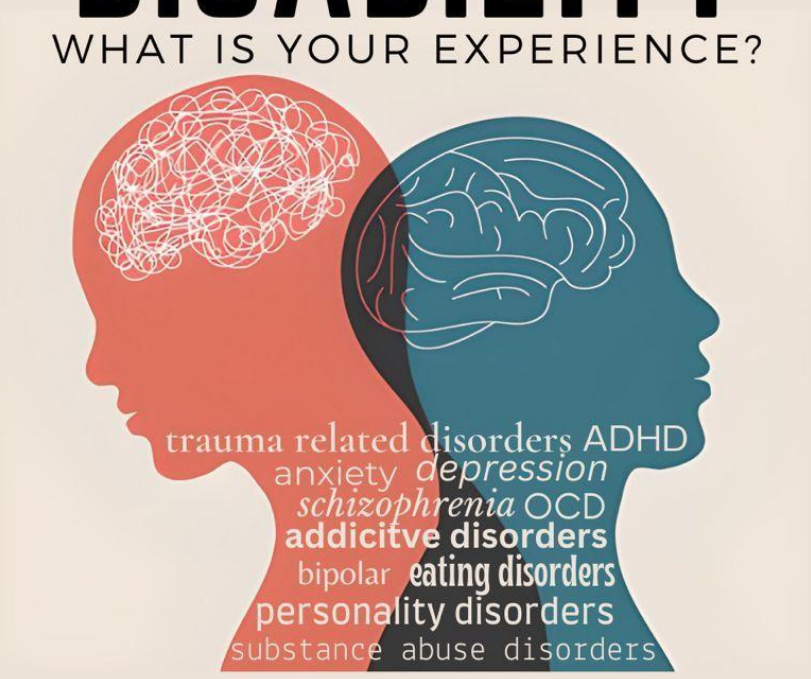
1. How did you find the interview, especially with regards to speaking about your family member?
2. Are there any intense feelings that were brought up for you during the interview process?
3. Would you like to discuss these feelings?
4. Do you have any questions that you still want to ask me about the interview or other aspects of the research process?
5. Are you feeling okay to end the interview here?

Thank you so much for your participation.

Appendix C: Advertisement

PSYCHOSOCIAL DISABILITY

WHAT IS YOUR EXPERIENCE?



DO YOU MEET THE FOLLOWING REQUIREMENTS?

~A MEMBER OF THE SOUTH AFRICAN INDIAN HINDU COMMUNITY.

~LIVE(D) WITH A FAMILY MEMBER THAT HAS A PSYCHOSOCIAL DISABILITY

~18 YEARS OR OLDER.

~AVAILABLE FOR A 1 HOUR INTERVIEW (ONLINE OR IN-PERSON).

IF SO, PLEASE CONTACT:
SUMAYA HABIB
083 878 0922
1604200@students.wits.ac.za

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT
PSYCHOLOGY

CLINICAL PSYCHOLOGY MASTERS STUDY

Appendix D: Participant Information Sheet

Participant Information Sheet

The South African Indian Hindu community's understandings and experiences of psychosocial disability

My name is Sumaya Habib, and I am a Clinical Psychology Masters student at the University of the Witwatersrand. I am currently in the process of collecting data for my Masters research project and I would like to invite you to be a participant in my study.

This study aims to find out how people in the South African Indian Hindu community in Johannesburg, who have family members with a psychosocial disability, understand and experience psychosocial disability in their everyday lives. 'Psychosocial disability' refers to dysfunction or impairment in a person's emotion, cognition, or behaviour as a result of social, biological and psychological factors, that prevents an individual from functioning in society. Some examples of psychosocial disabilities are: mood disorders, anxiety disorders, schizophrenia, and trauma-related disorders.

This study will require you to take part in an interview (that will be between 45 minutes to 1.5 hour) where you will be asked questions about your experiences with, feelings, thoughts and understandings of psychosocial disability, especially in relation to your culture. Before the start of the interview, you will be asked to sign a consent form. Please read through the consent form carefully before signing it. Signing the consent form shows that you are willing to participate in the study and that you agree to all the conditions of the study. However, if you feel uncomfortable or overwhelmed during the interview, you may choose to withdraw from the study up, until the end of data collection, with no negative consequences. Your participation in this study is completely voluntary. You also have the right not to answer a question/s.

This interview will either take place online through an online platform called Zoom or preferably in-person in a place and at a time convenient for you. For purposes of analysis, your interview, will be audio recorded.

Different methods will be used ensure that the information you share with me about your yourself and your family member will be protected during the research process. Firstly, the email platform through which we will communicate will only be accessed by me, the researcher. Secondly, during the interview, we will either be using Zoom, in which a unique

password and ID is required to enter the meeting, thus ensuring that only you and I (the researcher) can access the online space. Or the in-person interview will be in a private, secure, and safe setting. Thirdly, the audio recordings from the interview will be stored on a password-protected computer only accessible to me, the researcher.

To further protect your identity, when the interview is transcribed, your name will be replaced with a false name (pseudonym) and easily identifiable information of yours and your family member will be removed or slightly changed. Additionally, my supervisor will only have access to these edited transcripts, not the original recordings. This research study will be written up as a research report, which will be available on the university library website, and possibly in publications and/or conference proceedings. The above measures ensures that your identity will be protected in the research report.

With your permission, other researchers many use the data collected from this research study, but your name and any personal information will not be used or passed on.

If you have any further study-related questions or concerns, you are welcome to contact:

Researcher:
Sumaya Habib: 083 878 0922
1604200@students.wits.ac.za

Supervisor:
Dr Clare Harvey: 076 473 8242
clare.harvey@wits.ac.za

Although the interview questions have not been designed to cause any discomfort or disadvantage you in any way, they have the potential to bring up sensitive information or disclosures surrounding psychosocial disability. If you feel overwhelmed at any time during the interview, we can stop. Or after the research process, you can contact the following free local counselling services:

Wits Students Crisis Line (24hr emergency line): 0800 111 331

Counselling and Careers Development Unit (CCDU): 011 717 9140, info.ccdu@wits.ac.za

Paballo Lepota at the Emthonjeni Counselling Centre at the University of the Witwatersrand: 011 717 4513

Furthermore, if you have any major concerns about how the study was conducted or your treatment during the study, please contact:

The University of the Witwatersrand Human Research Ethics Committee: 011 717 1408, Hrecnon-medical@wits.ac.za

Your participation would be greatly appreciated.

Kind regards

Sumaya Habib

Appendix E: Consent Form

Consent Form

The South African Indian Hindu community's understandings and experiences of psychosocial disability

This study aims to explore how members of the South African Indian community in Johannesburg, who have a family member with a psychosocial disability, understand and experience psychosocial disability, specifically in relation to their own cultural group.

By signing this section of the consent form I.....acknowledge the following with regards to Sumaya Habib's study:

- The research study was explained to me and I understand what this research process entails
- I agree to take part in an in-depth interview
- My participation is completely voluntary
- I can withdraw from the study at any time during the data collection stage, without any negative consequences
- My identity and personal information will be kept confidential and anonymous through the use of pseudonyms, limited access and omission of significant personal details
- My interview responses will be used in the write up of a research report, towards the completion of a Masters degree in Clinical Psychology
- Anonymised, direct quotations can be used in the write up of the research report
- The findings can be used in possible publications and conference proceedings

…… (signature)

By signing this section of the consent form I.....acknowledge the following with regards to Sumaya Habib's study:

- The interview will be captured through audio recordings
- The recordings and transcript will be kept on a password protected computer that will only be accessible to the researcher

…… (signature)

By signing this section of the consent form I.....acknowledge the following with regards to Sumaya Habib's study:

- The completely anonymised data from this study can be used as secondary data by researcher colleagues, depending on their own ethics clearance being obtained.

…… (signature)

..…….. (name of participant)

…… (date)

…… (signature)

..…….. (name of researcher)

…… (date)

If you have study-related questions you are welcome to contact:

Researcher:
Sumaya Habib: 083 878 0922
1604200@students.wits.ac.za

Supervisor:
Dr Clare Harvey: 076 473 8242
clare.harvey@wits.ac.za

The following are details of free services that you can contact if you feel overwhelmed at any time during or after the research process:

Counselling services:

Wits Students Crisis Line (24hr emergency line): 0800 111 331

Counselling and Careers Development Unit (CCDU): 011 717 9140, info.ccdu@wits.ac.za

Paballo Lepota at the Emthonjeni Counselling Centre the University of the Witwatersrand: 011 717 4513