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MA CLINICAL PSYCHOLOGY

A systematic literature review on socio-emotional experiences of those living with a disability in South Africa.

by

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Research Report

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Abstract

The aim of this systematic review was to review existing and available literature on the socio-emotional experiences of disabled South African people regarding their disability. Relevant peer reviewed journal articles over a twenty-year period (2000-2020) were reviewed. Data collection was conducted by searching the following databases: EBSCO Host (CINAHL, MEDLIN, Psychology and Behavioural sciences collection), Sabinet and Sabinet African journals, PsychInfo, PubMed, and Taylor & Francis. Thematic synthesis was used to analyse data. Findings of this research revealed nineteen studies that fully met the inclusion criteria. Thirteen descriptive themes emerged including: positive experiences, need to motivate others, need to belong, the paradox of dependence and independence, negative emotions, constant fear of discrimination, shutting up, vulnerable, and the use of humour as a security to secure relationships. Furthermore, analytical themes that were further analysed from the descriptive themes produced four themes: experiences of various emotions, emotional needs in people with disabilities, disabled people finding themselves in unsafe environments, and taking back control.

Keywords: disability experiences; disabled; socio-emotional; systematic literature review; South Africa

Chapter One: Introduction

People living with a disability not only face various experiences in terms of their personal lives and contexts in which they live, but they also face various socio-emotional experiences in relation to their disability. Socio-emotional experiences in this context relate to the emotional experiences of disability in relation to the society. Disability studies have evolved in significant ways over the past three decades, and voices of the disabled have emerged after a transition from the medical model to a social model where lived experiences of disabled people are explored (Neille, 2020).

Although lived experiences of disabled people are explored, the focus has mainly been the socially-related experiences in terms of their environment. Thus, conflicting views regarding emotional experiences have been recorded in the literature as well as no specific theory to explain these experiences. Furthermore, little is known regarding emotional experiences when exploring the lived experiences of disabled people. Therefore, socio-emotional experiences of those living with a disability have been largely excluded from disability studies.

This research aimed to systematically review existing, available literature on the socio-emotional experiences of disabled South African people regarding their disability.

This first chapter of this research will introduce the research by discussing first the background and context, the research problem, the aims of research, the significance of this research, important definitions, and lastly the rationale for this study.

Background to the research

Disability studies have evolved in significant ways over the past three decades, and voices of the disabled have emerged after the introduction of the social model where lived experiences of disabled people are explored (Neille, 2020). Furthermore, disability studies experienced a shift from a medical model of disability which focused on non-normativity of the disabled person (Harvey, 2015). This view of disability sees disabled

individuals as having been “failed by biology” (Neille, 2020, p. 2), thus experiencing discrimination, social exclusion, and stigma from the environment. This problematic model was then replaced by the social model of disability, which focuses on social issues of discrimination and exclusion (environmental factors). From this perspective, experiences of exclusion emerge from sociopolitical settings, such as lack of wheelchair ramps in environmental settings (McKenzie et al., 2014). Thus, radical perspectives on disability have attempted to ground their analyses in sociology (Shakespeare, 1993).

Although emphasis has been made on societal structures (Shakespeare, 1993), attention directed to psychological (emotional) aspects of disability and the disabled experience has developed more recently in the literature. Yet there is still a dearth of literature exploring these emotional experiences (Watermeyer, 2016). Regarding psychological experiences of people with a disability, the social model has not addressed how disabled people feel about their disability. Exploring these socio-emotional experiences has received controversies in disability studies (Watermeyer, 2016). The hesitancy regarding exploration of emotional experiences in disability studies has been attributed to the caution of confirming hateful ideas about disabled people (Watermeyer, 2016). However, the existence of these socio-emotional subjective experiences cannot be ignored.

Social and economic predictors of disabled people have been studied extensively; however, the subjective, emotional nature of experiences of disabled people have been largely excluded (Watermeyer & Swartz, 2016). Some advocates for the social model of disability have rejected earlier psychological theories that assumed disabled people will have psychological problems because of their disability. This frame of mind developed as a result of psychological theories being seen as continuing discrimination and invalidation because under the medical model perspective they psychopathologised an already medicalised view of disability (Watermeyer & Swartz, 2016). Furthermore, attitudes from psychological research towards disability did not attempt to question individualistic understandings of impairment (Shakespeare, 2018). Thus, emotional vulnerabilities of disabled people have been avoided by the social model with its focus mostly on activism

and resistance. Given the complexity of disability, emotional experiences of disability have largely been ignored in literature.

Research problem

Globally and nationally, emotional experiences of disabled people have gained popularity. It has been found that disabled individuals from different societies have lived different lives, as cultural reactions are diverse (Shakespeare, 2018). On a global scale, Namkung and Carr (2020) argued that impairment is associated with increased symptoms of depression and daily compromised mood, satisfaction of life, and self-esteem. Similarly, D'Amanda et al. (2020) found reduced mental health, quality of life, and relationship strain were common phenomena in these disabled individuals. In South Africa, there is a dearth of literature regarding the socio-emotional experiences of disabled people. Furthermore, it has been reported that prevalence of stereotypes that disabled people face can leave them feeling isolated and reluctant to acknowledge their own losses, as well as prevent them from developing a deeper understanding of themselves (Watermeyer, 2014). Watermeyer (2014) reported in his experience of working with disabled people as a psychotherapist that loss is a common theme. Rule and Modipa (2012) examined the attitudes and experiences of adult disabled people regarding education in rural KwaZulu Natal province. Findings highlighted issues such as discrimination, feelings of isolation, and sadness. Similarly, Swartz et al. (2020), on a comparison between racism and disability, reported that the discrimination that disabled people face is alarming. In contrast, a study conducted in Mitchells Plain, Cape Town, on the experiences of wheelchair users found that participants had differing views regarding their own emotional experiences with their disability (Schnitzler, 2020). These views ranged from separation, status, loss, worries about others' perceptions, and acceptance, to trying to distinguish themselves from these stereotypes and disability, and believing their mind is still active. A literature review suggests that there is a small, but growing body of research that highlights emotional experiences of people with a disability, about their disability. As such, one limitation of past studies is a concentration on the social experiences of disabled people and less concentration on the emotional experiences. Meaning that relatively little is known by disability studies researchers about different emotions that are experienced

by disabled people. If disability studies researchers seek to know and better understand the socio-emotional experiences of disabled people, reviewing these experiences will shed light on what has already been done and what is lacking in this field.

Research aims, objectives and questions

Given the dearth of literature regarding socio-emotional experiences of disabled people in South Africa, this research project systematically reviewed existing, available literature on the socio-emotional experiences of disabled South African people regarding their disability. Further, this study will identify psychological theories attached to socio-emotional disability experiences.

Justifications/ significance: Why this research is worth conducting

This research will help contribute to the body of knowledge regarding socio-emotional experiences of disabled people in South Africa. It will address what disability studies have covered regarding these experiences, gaps regarding these experiences, as well as make recommendations regarding potential future research.

Defining disability

The historical definition of disability focused on the nature of impairment and the alignment of the body, or deviation from, socially constructed norms (Neille, 2020). This definition was problematic in that disabled individuals were viewed as “failed by biology” (Neille, 2020, p. 2). Furthermore, the medical model placed individuals with a disability as unfortunate, and those that are non-disabled to be charitable towards them (Shakespeare, 2018). To date there has been little agreement on the exact definition of the term ‘disability’ as it is broad and multidimensional (Shakespeare, 2018). It is therefore an umbrella term that covers a multiple range of impairments that limit participation within sectors of society and restrict certain bodily functions (Tinta et al., 2020; WHO, 2011). Given the diversity of disability, it is complex to categorise and definitions differ from country to country (Potgieter, 2016; Shakespeare, 2018).

In a South African context, disability has been classified into six categories, namely sight, hearing, communication, physical, mental, and difficulty in self-care (Stats SA, 2014). It is important to note that disability can be congenital (born with) or acquired. The latest definition defines disability as an interaction between the body, the person, and the society where the person exists (McKenzie et al., 2014; Naidoo et al., 2017; WHO, 2011). It is important to highlight that the current definition of disability still excludes the emotional aspects of disability. The adopted definition for the current study is any condition that impairs ability to perform activities of daily living lasting six or more months (Namkung & Carr, 2020; Wegner & Rhoda, 2015).

Prevalence of disability

Research has reported the global prevalence of 15% of the world's population has a disability which makes up around one billion people living with some form of disability (Dada & Morwane, 2021; Shakespeare, 2018; Trani et al., 2020). Approximately, one in seven people live with a disability. This current estimated prevalence has been reported to be rising, with a significant portion of people with a disability in low- to middle-income countries, such as South Africa (Dada & Morwane, 2021). Interestingly, South Africa has a 10% higher than the world average prevalence of people with a disability, with a rate of 25% (Naidoo et al., 2017; Tinta et al., 2020). Nevertheless, Shakespeare (2018) argued that these prevalence rates may be misleading as disability is complex and often underestimated. Furthermore, the complexity of formulating and defining disability may contribute to difficulties in estimating prevalence (Heled, 2020). In some ways, most lives are touched by disability. Thus, an experience of disability can affect anyone.

In the past, specifically in the 1960s, people with a disability often lived in residential institutions, attended segregated schools, most did not work, and public transport and buildings were inaccessible for disabled people. This period was dominated by a medicalised model of disability. In Britain, a disabled movement was founded by the British Council of Organisation of Disabled People in 1981, which represents various national and local organisations for disabled people. This is where Disabled International

was founded, with a slogan ‘nothing about us without us’ (Shakespeare, 2018, p. 25), which was a breakaway from Rehabilitation International (Shakespeare, 2018). This movement had two major contributions: it identified a strategy to eliminate barriers that disabled people face in society, as well as replacing a deficit approach to disability in the medical model with the social model of disability focusing on social oppression. This thinking influenced a new way of thinking about disability beginning with disabled people themselves, which helped them to become empowered and to live independent lives. It was under this transition within the disability movement that new ways of enquiring about disability came about. Furthermore, understanding of experiences of disability were to be explored from social perspectives (Shakespeare, 2018).

The nature and rates of disability are influenced by context. One of these is the concept of disability prevalence, which is a complex exercise since it involves gathering and presenting data on a large number of people with various impairments. Before the advent of the International Classification of Functioning (ICF), this concept was only presented through a medical model. The concept of disability prevalence was then conceptualised through the introduction of the ICF. Its conceptualisation led to the realisation that the prevalence of people with disability would be influenced by the varying contextual differences within a population such as resourced and under-resourced communities (Maart et al., 2019; Sadiki et al., 2021).

Study rationale

Watermeyer (2013) reported that the shortcomings of current disability studies is giving little to no attention to psychological (emotional) experiences of people living with a disability and to those experiencing disability in another person they encounter. Furthermore, the disability movement has favoured political strategy which favours materialistic aspects of disability (physical barriers), which emphasises disablement, exclusion, and oppression from society (Shakespeare, 2018). The social model movement against social oppression followed a well-established political path that denaturalised forms of oppression, by demonstrating that the view of disability as biological and unchanging was as a matter of fact the response to disability

(Shakespeare, 2018; Watermeyer, 2013). The main contribution from this model was speaking against the impact of a disabling society to disabled people, as well as dismantling these disabling barriers, and social transformation (Shakespeare, 2018). However, a major problem with this kind of model is the failure to include subjective, and particularly for the current study, emotional aspects of disability (Neille, 2020; Watermeyer & Swartz, 2016).

In contrast, Watermeyer (2013) pointed out that emotional responses to disability exist and have an enormous impact even though these are often not acknowledged. There is a growing body of evidence suggesting that disabled individuals experience various psychological experiences related to their disabilities, such as depression, helplessness, isolation, feelings of belonging to an outgroup, discrimination, stigma, and various frustrations (Badenhorst et al., 2020; Schnitzler, 2020; Stern et al., 2020). However, psychological experiences are not limited to negative feelings. Experiences differ significantly due to the diverse nature of disabilities; thus, disabled people potentially have different experiences to one another and to able-bodied people, and may feel differently regarding their lives (Shakespeare, 2018). Furthermore, significant differences in experiences are prevalent, especially between those that are born with a disability and those that acquire a disability.

On the other hand, literature has consistently argued that stigma projected onto disabled people by others (non-disabled) affects their emotional experiences (Shakespeare,1993, 2018; Trani et al., 2020; Watermeyer, 2014). Furthermore, growing interest in psycho-emotional aspects of disability has focused attention on internalised oppression, and the disablist socialisation: what disabled people think about themselves in the context of how society views disability and feelings associated with discrimination based on their disability (Watermeyer, 2018).

Therefore, studying the emotional experiences from the disabled individual's perspective is vital as there is an important lesson to be learned from actual stories of disabled individuals (Swartz, 2014). Furthermore, this area of study is important considering

research is limited on the topic of psychological ramifications of disability, especially considering that research has pointed out that stigma has a negative influence on disabled people's emotional experiences.

The purpose of this study was to demystify psychological experiences that individuals with disabilities experience, as well as shed light on what further research is needed in accessing feelings disabled people report regarding their disability. The findings of this study may further assist clinicians working with disabled people to understand these emotional experiences and lean towards viewing disability as having many dimensions, such as functional limitations, environmental and social factors, together with the emotional aspects of the disabled experience.

Thesis structure outline

In Chapter One the context, research questions and aims, the values of the research, important definitions, and the study's rationale have been identified. In Chapter Two, the existing, relevant literature will be reviewed in order to identify key socio-emotional experiences of disabled people, including the study's theoretical framework. In Chapter Three, the method (systematic review) and research design will be justified. Furthermore, findings will be presented in Chapter Four, and discussion of these findings as well as conclusion will be discussed in Chapter Five.

Chapter Two: Literature Review

Introduction

The recognition of disability has increased over the last twenty years. This has led to the development of different theories and viewpoints of disability in various countries (Schneinder, 2009). Many theories in disability studies have adopted exploring the lived experiences of people with a disability, mainly emerging from a medical model of disability (Neille, 2020). However, the key shortcomings in disability studies have been the limited engagement with the emotional level of this experience (Watermeyer, 2013). In other words, there is a dearth of literature on socio-emotional experiences of disability as research has placed attention on mostly material barriers faced by disabled people (Haegele & Hodge, 2016; Neille, 2020; Watermeyer 2012, 2016). Although some literature covers a variety of socio-emotional experiences of the disabled, the majority of literature does not dedicate the entire research project on emotional understandings of this experience. This literature review will focus briefly on theories attached to socio-emotional experiences of disability, themes covering emotional experiences of people living with a disability about their disability in various contexts, including gender, culture, and socio-economic statuses.

Theoretical framework of socio-emotional experiences of disability

The medical model

Individuals with differences in their bodies and minds have been excluded from society for hundreds of years (Swartz et al., 2020). As a matter of fact, during the Nazi regime, the first people to be killed were not because of their race, religion, or sexual orientation. They were killed due to their disability. This was based on Hitler's view that disabled people were 'useless feeders', draining state resources that were already limited, and thus were worthy to be exterminated (Swartz et al., 2020). This was a prominent perception of disability under the medical model of disability. Under this model, disability was largely viewed as an impairment or underlying health condition that needed to be cured (Shakespeare, 2018). The focus of this approach was mainly on adjustments to

impairment. The medical model of disability did not have room for subjective experiences of people living with a disability, as its focus was on the supposed pathology of disability, thus disability was regarded as an individual problem. The focus of intervention was usually on individuals. This approach to disability has been criticised by individuals and groups within the disability rights movement. Furthermore, the medical paradigm has been chastised for failing to consider contextual issues that disadvantage disabled individuals (Watermeyer, 2013). This criticism is often reflected in the documents that the South African government has adopted in 1997, that of Office of the Deputy President (ODP) (Schneider, 2006). The disability movement rejected this medical model as it viewed disability as a personal misfortune (Shakespeare, 1993). The social model was then proposed to offer a different understanding and perception of disability.

The social model and disability

The social model was a shift from a deficit approach of disability to a view of disability as a result of social oppression (Shakespeare, 2018; Swartz et al., 2020). The social model states that the 'problem' is situated in the environment. Furthermore, the environment has a significant role to play in defining disability. According to experts (McKenzie et al., 2014; Naidoo et al., 2017; WHO, 2011), disability is an experience that occurs when a person encounters a health condition and their environment. It further states that aside from the physical features, factors such as the environment also play a role in determining the experience of disability, thus looking at both the environment and the individual is crucial in order to describe disability experience in an accurate and comprehensive manner. The environment includes the various elements of a person's external world, including their physical world and how it is organised. The environment can help people with physical and mental health conditions function better by providing them with the necessary equipment and services to support their daily activities. However, it can also create barriers to achieving these goals by excluding people with impairments from various facilities and services (Schneider, 2006; Watermeyer, 2014).

The social model scholars argued that failure to provide adequate support for individuals with particular needs has led to the exclusion of persons with disabilities contrasting the medical model which emphasises the individual with a disability. Consequently, making a distinction between impairment and disability. The construction of disability under the social model is due to limitation of opportunities or loss of participation in the community due to physical or social barriers (Watermeyer, 2013). In this regard, the 'patient' is the society itself (Watermeyer, 2013; Watermeyer & Gorgens, 2013). This model addressed complex layers of issues that were barriers to participation of those that are living with a disability. The probing questioning of the social model seeks to reveal multiple layers of oppression woven into society's core structure. Being disabled meant experiencing certain social restrictions that are inflicted by society that is highly discriminatory. At its extreme, the social model interpreted disability as a social accomplishment and completely material (Shakespeare, 2018; Watermeyer, 2013, 2016).

The social model is an essential conceptual point in the development of disability theory, and without it the enormous changes in viewpoints of disability would not have occurred (Watermeyer, 2013). The model uncovered environmental factors and other materialistic factors that perpetuate discrimination of disabled people. However, the disability experience is not only limited to societal factors, but there are also emotional experiences of disabled people which are still not addressed within this model (Watermeyer, 2013). Disability studies writers do not agree with the idea that people with disabilities have emotional distress. Some discourage any exploration of disabled peoples' inner life. The historical materialist model of society assumes that the psychological realm is a diversion from the real world (Watermeyer, 2014).

Emotional expression of disability is often constrained by social pressures and political correctness. Disability is overwhelmingly regarded as a negatively valued identity, with associations of loss, damage, and deficit, these views persist even under the social model of disability (Goodley et al., 2012; Watermeyer, 2014). The traditional models of disability rely on the theories of grief and bereavement, that disability requires to be grieved and accepted. This view assumes that people with a disability experience a series of stages of loss and acceptance because of their disability. The global disability movement has

been reluctant to acknowledge the sometimes harmful psychological effects caused by discrimination based on impairment (Watermeyer, 2016). Therefore, the social model falls short in mirroring disabled people's experiences completely, as it excludes emotional aspects. The social model was solely focused on material exclusion barriers, which are prominent to certain people. This model ignored the emotional experiences of disabled people, as exploring these kinds of experiences poses a huge risk of confirming the medicalising views of the model. Thus, arguably, seeing disability as everything to do with barriers and nothing to do with individual impairment served to address discriminatory and oppressive prejudices regarding disabled people, but overlooked emotional ramifications of these experiences.

Furthermore, key theorists have not devoted enough attention to the question of representation and meaning, as the focus has been largely material. This view is, however, misguided (Shakespeare, 1993). Most depictions of disability in sociological studies gloss over the various aspects of disablism. Conceived as firmly within sociology, radical views of disability have rejected the explanations of psychologically inclined explanations. Nonetheless, the social model has contributed largely in addressing discrimination, as well as the relationship with disability and varying cultural representations of disability and society (Shakespeare, 2018).

While it is important to preserve the importance of material barriers to inclusion, it is also true that the experience of social harm can foster valued identities (Watermeyer, 2016). Studies on disability have avoided exploring the emotional experience of people with disability, as it was thought that this might worsen stereotypes attached to disabled people. However, treating people with disability as inferior has been shown to have psychological harm (Watermeyer, 2016). Thus, this report argues that psychological harm needs to be explored as there is much research that shows that discrimination and exploitation of disabled people exists. Furthermore, the materialist focus of disability studies has helped maintain an unconscious assumption that disabled people are psychologically unaffected by their 'suffering' (Morwane & Dada, 2021; Swartz, 2015; Trani et al., 2020; Watermeyer, 2016). While it is important to preserve the importance of

material barriers to inclusion, it is also true that the experience of social harm can affect the disabled person's identities. Furthermore, stigma is often linked to the negative effects of mental health conditions and can create a depressed state of mind and a lower self-esteem, as the experiences of persons with disabilities is not limited to the physical realm (Trani et al., 2020; Watermeyer, 2012).

Psychoanalysis and disability

Despite the huge contribution of the social model in understanding the environment and the individual with a disability, Watermeyer (2006) argues that modes of inquiry that fail to explore the influence of disablist oppression will ultimately lack satisfying the needs of the study of disability, as the emotional life of disabled people is part of their experience. Thus, the psychoanalytic lens to disability has been proposed to understand emotional experiences of those living with a disability. The psychoanalytic lens allows the examination of how images and ideas of disability are experienced by all of us, and how these shape the ways in which society, including those with a disability, views persons with disability, as there is often a conflicted emotion involved in responses to disability. If disability evokes such strong feelings in people, then these could influence how disability is viewed and experienced. The uneasiness that is evoked in people about disability makes it a crucial issue to which psychoanalysis draws our attention.

Psychoanalysis was introduced by Sigmund Freud who argued that there is a part of thoughts that is outside of consciousness which he named the unconscious in the late nineteenth century (Watermeyer, 2006, 2013). To explain this psychoanalysis theory briefly, it states that there are elements of emotional experience that are difficult to bare and consequently maintain in awareness and feelings that seem difficult to bear. As a result, these aspects of painful feelings and memories are kept away in the unconscious by defense mechanisms. Defense mechanisms are used by the psyche to safeguard conscious thoughts from emotions that would rather be forgotten or rejected entirely (Watermeyer, 2006, 2013).

According to psychoanalytic theory, human experience is made up of both joyful and extremely painful aspects and everyone has at some point in life, worried about not being good enough for others (Watermeyer, 2006). This is not any different for people who are living with a disability; however, in some cultures the idea of disabled people is attached to certain unwanted parts of our experiences. Disabled individuals have come to represent the most broken, undesired, ashamed, and unwelcome aspects of humanity (Watermeyer, 2006). Unlike the social model has suggested, many people who are disabled experience their disability as being ambiguous and shaded, not as entirely impairment or entirely socially produced. For an example, as mentioned by Watermeyer (2006), French describes her life as being affected by discrimination due to her sight impairment. She also mentions that there is a layer in her difficulties between the body and society. Thus, the social and psychoanalytic models of disability are important to consider as they look at both the environment and the disabled individual.

The psychoanalysis model will contribute to disability studies by becoming a medium that examines the intra-psychic world, and making sense of how this realm relates to reality. In the case of disability, psychoanalysis tackles the idea of how disability can trigger defensive mechanisms that can distort perception (Watermeyer, 2006). Research regarding psychoanalysis and disability is still at an infant stage. Hence, researchers who believe in a materialistic view of understating the disabled experience deem exploration of emotion or "the internal world" of disabled people as a diversion from the ‘real’, tangible challenges of social oppression faced by disabled people.

It is important to note that when relating to disability, psychoanalysis has given significantly little attention to theorising disability. According to the limited evidence, psychoanalytic views, like other psychological theories on disability, assume that bodily damage leads to some type of psychopathology, which is at the centre of the argument of the social model, hence attributing emotional distress experienced by disabled people to barriers to participation. This view from the social model was made as not all people with a disability experience psychological distress, but a proportion will, as similar to other populations. Unfortunately, these views from psychoanalysis have perpetuated

prejudices that disabled people experience only negative emotions because of their disability, as some scholars have labelled disabled people as 'unanalysable' (Watermeyer, 2013, p. 59). Thus, the assumption has been that disability brings severe psychological damage (Watermeyer & Gorgens, 2013). There is a firm association between disability and loss in popular imagination, as discussed above. People with disabilities are often viewed as depressed, lonely, battling feelings of inadequacy, shame, and damage (Swartz et al., 2020).

In a South African context, Watermeyer (2013) suggested that emotional experiences of disabled people exist, although living in low-income countries can constrain this emotional life due to othering as well as isolation from society (Watermeyer, 2016). It is therefore critical for disability studies to explore these emotional lives. It is proposed in this research that an integrated psychological framework, using psychoanalytic theory, along with social factors from the social model of disability will be utilized as a theoretical framework to understand experiences of those living with a disability. This framework applies psychoanalytical ideas to social responses to disability, making sense of discrimination in its various ways and issues in disability politics and research. Therefore, a person's psychological (emotional) experiences are explored, while social oppressive forces are rigorously critiqued. This framework will demonstrate how, without pathologising marginalised people, it is possible to theorise the psychological mechanisms and impressions of a discriminatory society (Watermeyer, 2013) and the experiences of disabled people thereof. The current study will utilise this integrated psychological model of disability as its theoretical framework. Integration of these two models was chosen as a theoretical framework because psychological theorists assumed that the experiences of persons with a disability were associated with psychopathology (Watermeyer & Swartz, 2015) or resiliency (Watermeyer, 2014).

For most psychoanalytical work on disability, the idea that people with a disability are prone to psychological problems has been presented as a direct link between their conditions and psychological issues. A contextually grounded approach, on the other hand, foregrounds disablism. Conversely, the social model has emphasised the environment as the sole problem. As a result, this research argues that experiences of

disabled people are shaped by both their intra-psychic world (how they feel about their disability) and the environment, and these are not mutually exclusive. Therefore, relying on either model exclusively will fall short, as it will certainly exclude some important aspects of disabled people's experiences. Relying on the psychoanalytic model alone will undermine environmental barriers and discrimination that oppresses disabled people; whilst relying on the social model will exclude emotional experiences. It is argued in this research that to understand experiences of disabled people, it is paramount to look at both the social model and the psychoanalysis model interaction. Furthermore, many impairments, such as blindness or an inability to walk have an embodied reality that is different from the reality that they become disabled in the context of social exclusion (Swartz et al., 2020). However there is also an experience that occurs at a social level that could still be emotional.

Socio-emotional experiences of disability from a global perspective

Social relations and cultural values influence disability experiences. Disabled individuals from different societies have lived different lives, as cultural reactions are diverse, thus their experiences vary (Shakespeare, 2018). Disability is always influenced by social relations and cultural values, thus making disability not a natural phenomenon that is universally understood. Although illness and impairment have been experienced across all human existence, reactions to these experiences differ, ranging from elimination, fascination, inclusion, and even incarceration. Therefore, feelings regarding one's disability is dependent on individual experiences (Shakespeare, 2018).

Globally, studies of socio-emotional experiences of, and associations to, disability has only recently gained popularity. Namkung and Carr (2020) conducted a longitudinal survey with 7108 participants in the United States of America. The authors argued that impairment is associated with increased symptoms of depression and daily compromised mood, satisfaction of life, and self-esteem. These emotional experiences were said to be amplified by discrimination related to one's disability. The findings concluded that disability is a significant indicator for negative psychological outcomes (Namkung & Carr, 2020). It was further noted that this was the first study that looked at the direct link

between disability and aspects of psychological well being, which is not surprising considering the reported controversies regarding exploration of emotionality in disabled individuals. Similarly, another American study, looking at a heritable eye condition that causes significant visual disability, found reduced mental health, quality of life, and relationship strain were common phenomena in these disabled individuals (D'Amanda et al., 2020).

Another study, conducted with Chinese individuals aimed to investigate the interrelation between disability, social interaction, and poor psychological well being. Data used for this study was from the World Health Organisation's (WHO) study of global ageing and adult health. 8 771 people's responses were analysed. Findings suggest that a social life that is less active is explained by poor functional performance and psychological well being that is compromised (Hsieh & Waite, 2019). Furthermore, there was a clear difference between disabled and non-disabled people's psychological wellbeing, with disabled individuals reporting poorer psychological wellbeing.

Ethnicity and the experiences of disability

In societies such as rural parts of Africa, Asia, and Medieval Europe, where there is no fixed income, disabled people experience the same level of hardship and poverty as everyone else (Shakespeare, 2018). It is well documented that poverty can impact negatively on experiences of disability. Globally, disability prevalence is seeing an increase. In low middle class income countries, it is found that people with a disability face low education, low participation in the workplace, and are in abject poverty (Maart et al., 2019; Muthakhrishna, 2009). Thus there is a link between disability and poverty (Muthakhrishna, 2009). In poor countries, the prevalence of poverty has a negative effect on the mental health of persons with disability (Watermeyer, 2016). Stigmatising people with disabilities can make it far more difficult for them to ask for help. Also, it can make it challenging for them to overcome the stigma associated with their disability (Watermeyer, 2016). Furthermore, in parts of Africa, people with limited mobility are often targeted for violent and hate crimes.

From a study of ethnicity and disability in Cape Town, South Africa, Ali et al. (2015) found that the black African group had a higher proportion of participants with mild intellectual disability than the Caucasian group. The black African group was more likely to report being attacked than the other ethnic groups. They also believed that they were the victims of the same type of discrimination as the Caucasian group. With reporting a trend of higher levels of stigma. This study aimed to determine if the experiences of stigma vary depending on the ethnic group.

Congenital and acquired disability

Another significant difference between experiences of living with a disability is dependent on whether the individual is born with a disability or it is acquired. Those born with a disability may tend to generally feel that it is part of their identity that their life cannot be imagined without it, especially that they have nothing to compare it to. This reduces the pressure of 'wanting to come to terms with their disability'. Hence, the main challenges they face is access to education and employment. They may also have poor self-esteem, depending on how they were brought up (Shakespeare, 2018). Furthermore, individuals with acquired physical disabilities may have lost their confidence and capacity to interact with others.

Conversely, acquiring a disability late in life is an advantage in some ways, as these individuals may have received a good education, have a career, and a family, as well as good self-esteem. However, the shock or trauma that might be attributed to acquiring a disability, especially if they had preconceived ideas that disabled people are inferior, may exacerbate the shock. Thus, 'overcoming' the disability might be wanted. Research has proven that many people with a disability feel good about their lives, opposed to what may have been thought, an in other circumstances, better than those of able-bodied people. How one is regarded by others is often different from one's subjective state. Also, an individual who is regarded as disabled may not feel that they are disabled (Shakespeare, 2018).

Disability experiences and gender

Women have been subjected to various forms of discrimination and prejudice. In both the West and African patriarchal society, women are often restricted to subordinate positions. The assumption that women are inferior and less valued compared to men is often used to describe disability (Majiet & Africa, 2015; Mehrotra, 2006). Women are defined as disabled before being considered as women, this can lead to a cultural identity loss. For instance, in some cultures, it is assumed that girls with disabilities are not capable of providing for themselves and cannot marry. In addition, women with physical disabilities often face various structural and social stereotypes that limit their experiences. This is in part due to the fact that they are not expected to have a full social role in society. Internationally, it has been observed that women with physical disabilities experience double oppression (Majiet & Africa, 2015). Experiences of disabled women has been mostly a personal account, with some of being a disabled woman in a male-dominant society as very different from being a disabled woman in a society that is dominated by able-bodied people, a case that triples if they are from a disabling world (Mehrotra, 2006). Disability stereotypes undermine roots of womanhood, leaving women feeling inferior to others, resulting in some women expressing self-loathing (Shakespeare, 1993). Furthermore, compared to able-bodied women, disabled women and girls face various forms of human rights abuses, such as exploitation and abuse. They are also vulnerable to various forms of discrimination as a result of their social isolation and reliance (Grobbelaar-du Plessis, 2007).

Exploitation and disability

There are many cases where people with learning difficulties were befriended and exploited for their welfare benefits. These individuals were then subjected to various violent acts, usually carried out by non-disabled people (Shakespeare, 2018). People with other impairments can list numerous instances where they were verbally and physically abused by non-disabled individuals. Many of these instances are due to the various barriers that people with disabilities face. For instance, a person with mobility impairment may not be able to run away from an assailant. Also, those with a language or hearing impairment may not be able to communicate clearly. Conversely, some tend to develop

good communication skills and a sense of humour as an adaptive response to disabled stereotypes and discrimination. Oftentimes they have to make a joke to alert the non-disabled that they are well. If they want to have a seamless conversation with the non-disabled person, the impaired person must first put them at ease. When disabled people live in the community, they are also at risk. Bullying, abuse, and violence cause fear and harm for disabled individuals, and can even lead to death. Even disabled persons who have never been exposed to such severe beliefs live in fear and alter their daily routines to avoid places they consider to be dangerous (Shakespeare, 2018).

Socio-emotional experiences of disabled South Africans

Conceptions about disability or persons with disabilities could be misleading, since disability is a deeply personal experience (Sadiki et al, 2018; Watermeyer, 2006). Watermeyer (2014) reported in his experience of working with disabled people as a psychotherapist, loss is a common theme. This loss ranges from the usual experiences of discrimination and various traumatic life events. It is a misleading stereotype to suggest that people with a disability are mourning the loss of their ideal body. In reality, they are still dealing with the effects of other losses in their lives.

The prevalence of these stereotypes can leave people with a disability feeling isolated and reluctant to acknowledge their own losses (Watermeyer, 2014). It can also prevent them from developing a deeper understanding of themselves. The world does not want to hear about loss, and it makes people more likely to shame themselves for feeling ashamed (Watermeyer, 2014). Expressing feelings of sadness or loss may seem like a recipe for disaster. Knowing that they will be judged by default through the lens of the disability stereotype of damage and weakness can lead disabled people to remove evidence of these characteristics from their public persona (Watermeyer & Swartz, 2008; Watermeyer, 2009, 2016). Thus loss is due to social suffering (Watermeyer, 2014).

Regarding socio-emotional experiences of disabled individuals in South Africa, it is of importance to note that there is a dearth of literature on studies that exclusively explore how disabled people feel about their disability. This is arguably attributed to the

controversies that surround psychology theory regarding disabilities (Watermeyer & Swartz, 2016). The fear regarding exploration of emotional experiences of disabled people was an attempt to avoid perpetuating the hateful ideas regarding disabled people (Watermeyer, 2016). This ideology has since begun to change, as it was seen that subjective experiences of disabled people cannot be ignored (Watermeyer & Swartz, 2016).

Given that this current research is a systematic literature review, some of the findings in the disability literature in a South African context will be addressed very briefly here. This will be the case because the literature in the articles will be dealt with in more depth in the findings and discussion of the systematic review.

Rule and Modipa (2012) examined the attitudes and experiences of adult disabled people regarding education in rural KwaZulu Natal province. Findings highlighted issues such as discrimination, feelings of isolation, and sadness. Consequently, these experiences can be explained by the medical model narrative, which was used as a drive for segregation and silencing of disabled people (Neille, 2020). Watermeyer (2017) confirmed this by reporting that when he enquired about emotional experiences, individuals did not have resources to experience their emotions due to feeling like a burden because of their disability which results in a need to eradicate their feelings (Watermeyer, 2017; Watermeyer et al., 2019).

Swartz et al. (2020), compared racism and disability and it was reported that the discrimination that disabled people face is alarming, even in institutions that are keen for transformation and have such policies in place. The authors share their stories from interacting with higher education institutions. These authors are disability academic activists who are often left to deal with situations of exclusion and discrimination, this kind of treatment leave them with various feelings that will be discussed in their stories below (Swartz et al., 2020).

Story 1

A lecturer, with a visual impairment (completely blind) spoke about the demands of a blind lecturer. A task such as preparing presentation slides, is time consuming unlike his sighted colleagues. The author shared a conversation regarding extra work that needs to be done in preparation for lectures, it was highlighted that during this exchange, although the author's feelings were validated, there was a disregard of experiences through a cover of sameness, thus differences were overlooked. Furthermore, feelings that were evoked during this exchange were that of feeling silenced and unheard, as well as leaving the author questioning his own experiences as well as wondering whether these experiences were not important.

Story 2

The author shared experiences of needing accommodation in a university that offered a fellowship. It took time for the author to realise that needing support is justified. Furthermore, the author mentioned that it is hard to resist feelings of self-blame when unable to access the environment. Finding fulfilment and productivity in academic life was linked to accepting assistance that is needed.

Story 3

The author noted that their disability seems unrecognisable despite facing impairments such as inability to drive, inability to recognise people even when known, or draw money from the auto bank. Asking people for help occurs often, relying on strangers to do things that cannot be done unassisted because of one's disability. The author noted that the primary identity is not that of a 'disabled person', as there are many things that the author identifies as before calling oneself disabled. The author described being in an emergency strategic meeting, where the author listened for an hour and could not see the text that was being discussed. Other members of staff were able to see and read the document. The author then pointed out calmly that they could not see, and felt excluded due to inability to participate in the process. The author continued to explain that they could not see, even though the chair of the meeting replied that they thought the author could see. This made the author sit in silence, still unable to see the matter of discussion. Upon

deciding to ask once again for an electronic copy, the author displayed an angry tone due to feeling excluded. The author felt angry that one had to get angry to ask for something, and at the same time felt disappointed regarding feeling excluded and felt it would be much easier for everyone, and started to question if one was not disabled enough. These feelings are consistent with reports from Shakespeare (2018) and Watermeyer (2006) who suggested that disabled people tend to manage not only their feelings, but even those of the non-disabled.

In summary, it was argued that even in institutions that are eager to adapt, in a country where discrimination on the basis of disability is legally forbidden, casualness with which types of disability discrimination occur is astonishing (Swartz et al., 2020). A common theme in these personal stories, included when disabled people are faced with a difficult situation they blame or doubt themselves, which has been well reported in literature (Swartz et al., 2020). Thus disabled people are the ones that do the emotional work, which could sometimes include disabled people denying their disability, so as to collude with the non-disabled people (Swartz et al., 2020).

People living with disabilities encounter various challenges in accessing healthcare services and equipment. These issues are common in low- and middle-income countries. Aside from these, other factors such as poverty and political instability can also affect the lives of people with disabilities (Swartz & McKinney, 2021). It is also true that people with disabilities are often subjected to ridicule and hostility when they enter the public realm. Harassment is a concern for both men and women who are disabled (Shakespeare, 1993).

Van der Heijden et al. (2019) interviewed thirty women who have various disabilities, to investigate intersection of disability stigma and womanhood, as well as intimate partnerships in an informal settlement in Cape Town. The study showed that despite the prevalence of violence against women in the general population, persons with disability are still at risk for violence due to their disability. This includes financial abuse, neglect, and sexual violence. Swartz et al. (2018) further add that disabled people may suffer

symbolic violence directed at their self-identity which may be internalised by disabled people.

It was further argued that although disabled individuals are aware of policies and legislature on inclusion and their own interests in participation, they still experience a sense of loss of control and independence, facilitated by challenges encountered in environments which make them feel various emotions (McKinney & Amosun, 2020). Other differences were seen when healthcare outcomes and access to health for disabled individuals were compared to non-disabled individuals (Vergunst et al., 2019).

Recent studies outlined by Christa and Stacey (2020) suggest that students living with a disability are at a greater risk for depression, substance abuse, bullying, and fewer friendships. The reported reason for these circumstances is the negative attitudes and misconceptions from non-disabled individuals (Trani et al., 2020). Furthermore, it was pointed out that stigma may negatively influence the mental wellbeing of people with a disability. They additionally advocated that their findings suggest that stigma is the mediation factor in a strong association found between disability and higher depression rates, together with low self-esteem. Furthermore, prejudice and exploitation that disabled people face on a daily basis play a crucial role in the systematic exclusion of disabled people from mainstream society (Shakespeare, 1993).

Keikelame and Swartz (2016) conducted a study and analysed the subjective perspectives of people with epilepsy living in Cape Town, South Africa. The participants stated experiences of lack of empathy, skills, and treatment they received. Furthermore, they mentioned the fact that people often stare at them, which was dehumanising.

In contrast, a study conducted in Mitchells Plain, Cape Town, on the experiences of wheelchair users found that participants had differing views regarding their own emotional experiences with their disability (Schnitzler, 2020). These views ranged from separation, status, loss, worried about others perception and acceptance to trying to distinguish themselves from their stereotypes and disability and believing their mind is still active.

It is important to note that past research regarding emotional experiences of disabled people has mostly taken a qualitative approach, which is justifiable because the focus is on the subjective experiences of disabled individuals about their disability. However, Neille (2021) has suggested that it is important to take into consideration the place and context where these narratives are shared because some places may represent loneliness, segregation, social control, barriers to accessible services, and poor infrastructure.

It is apparent, based on this brief literature review, that there are few studies that focus directly on feelings of disabled people about their disability, and their direct associations between these phenomena seem to not be covered in previous studies. Attention to these aspects may reveal different emotions that are felt by disabled people, such as positive emotions that have not largely been reported. As mentioned above, disability studies place focus on materialistic aspects and have paid little attention to psychological experiences that exist, although not acknowledged (Watermeyer, 2016). Furthermore, literature is consistent in that these psychological experiences are largely influenced by stigma projected onto disabled people (Trani et al., 2020).

Conclusion

From the literature review, the social model of disability seems to be of dominance, exploring little regarding emotional aspects of disability. On the other hand, Psychoanalysis/psychological theories understanding of disability is conflicting. However, there is a small, but growing body of literature that is highlighting emotional experiences of people with a disability, about their disability. Although these findings are recent and are arguably still at an infancy stage. Literature consistently shows that emotional experiences of people with disability include fear, anxiety, depression, shame, as well as positive views, although limited. This literature review has highlighted that although researchers within the area of disability studies are beginning to pay more attention to socio-emotional perspectives of disabled people, there is still a gap in the literature regarding a range of these experiences. This systematic literature review study

will potentially reveal a comprehensive range of emotional experiences that are reported; these findings will demystify these experiences and give insights into future research.

Research aim

This research aimed to systematically review existing, available literature on the socio-emotional experiences of disabled South African people regarding their disability. It sought to gain in-depth knowledge of personal socio-emotional experiences as reported by disabled people in South Africa. Furthermore, this study aimed to identify psychological theories that are attached to socio-emotional experiences of disabled people. Additionally, gaps in literature, in relation to what has been studied regarding how disabled people feel about their disability, were identified. Lastly, to make recommendations where needed in cases of future research in the area of socio-emotional experiences of disabled people.

Research questions

1. What are the socio-emotional experiences of South Africans living with a disability?
2. What are the psychological theories attached to socio-emotional disability experiences?

Chapter 3: Methods

This chapter offers an overview of the research methods used in the study. The information that is provided in this section includes how the literature search was conducted and how the relevant literature was selected, as well as inclusion criteria for this study. The research design that was chosen for this study will be accounted for. The procedures and steps followed for the purpose of conducting this systematic literature review are also discussed. Furthermore, the methods used to analyse data are presented. Lastly, ethical issues are considered.

Research design

This study used a systematic literature review qualitative approach to answer the research questions. Qualitative research seeks to understand a phenomenon (subjectively or objectively) in different contexts (Bengtsson, 2016). Therefore, qualitative research relates to the process of getting closer to the phenomenon and understanding its meaning (Aspers & Corte, 2019). A systematic review, such as this was used in this study, seeks to search for, appraise, and synthesise research evidence systematically (Fynn, 2017; Grant & Booth, 2009). This is achieved as a systematic review is one that aims to find, evaluate, and consolidate the best available evidence on a given research subject in order to provide useful and evidence-based answers (Boland et al., 2017). Systematic reviews have a core requirement of problem or question definition, identifying and critically evaluating available evidence, and integrating findings (Boland et al., 2017). Systematic reviews help produce robust and broad conclusions by combining findings from multiple studies in a field. They allow for the collation of literature to inform future research and development (Laher & Hassem, 2020). Systematic reviews are not new, but they have not been commonly used in South Africa's psychology research field; however they provide alternative methods of obtaining study results that are comparable to those obtained with traditional research methods, such as cross-sectional surveys (Laher & Hassem, 2020).

Advantages

Systematic reviews can help identify the elements of a particular research study that will influence future research and practice by identifying available information on gaps, weaknesses, and trends (Aromataris & Pearson, 2014; Laher & Hassem, 2020; Munn et al., 2018). Furthermore, systematic reviews allow for a quick and comprehensive mapping of a particular area of study and provide a meta-commentary on trends across identified and examined studies that may allow further critical examination or discussion (Laher et al., 2017). The findings of systematic reviews provide useful and evidence-based answers. They are applicable to any type of study, and are systematic, explicit, and reproducible (Cooke et al., 2012). This form of review employs strict and precise steps to bring together the findings of primary studies in order to provide reliable answers to specific issues (Thomas & Harden, 2008). Furthermore, this design draws together all known knowledge of a given topic (Grant & Booth, 2009).

Disadvantages

Globally, this review method has evolved, and there are different acceptable methods for conducting detailed reviews. However, navigating the literature can be time consuming and complex, particularly because there is no single method for performing systematic reviews that is universally acknowledged (Laher & Hassem, 2020). However, the variations are minor depending on which set of guidelines have been followed by the researcher.

Rationale for choosing a systematic review research design

With the emergence of the social model of disability from the medical model of disability, factors such as environmental and materialistic aspects of the disability experience were addressed; yet emotional experiences of disabled people were not adequately addressed, even though they of course exist (Watermeyer, 2013). It is only until recently that the emotional experiences of disabled people are given greater attention, using both the social model of disability and psychoanalytic ideas to explore these emotional aspects (Watermeyer, 2013). Therefore, it was thought that the systematic literature review in the current area would assist in mapping and assessing existing information on, and gaps in,

socio-emotional experiences of disabled people in South Africa, allowing further knowledge development in this area (Cooke et al., 2012; Laher & Hassem, 2020; Mengist et al., 2019). By collating findings across disability studies on socio-emotional experiences, a systematic review provides an unbiased overview of what accumulated evidence says on this topic. Thus, providing robust conclusions, identifying relationships, contradictions, methods' flaws, gaps and inconsistencies in the research, and hence, providing future research direction. Lastly, existing theory, or development of new theories are evaluated with clear implications through this systematic review design. The research procedure followed in this study is one suggested for the discipline of psychology in the South African context (Laher & Hassem, 2020). Following this framework ensures a consistent and internationally acceptable framework. Therefore, current states, as well as knowledge or beliefs about socio-emotional experiences of disabled people are explored through the review.

Procedure

This study followed the eight stages of a systematic review and meta-analysis developed by Uman (2011). Systematic reviews follow an entire process of choosing, analysing, and collating all available evidence, whereas meta-analysis is the statistical approach followed to merge systematic review data. Thus, they both combine and analyse studies performed on a given research topic (Ahn & Kang, 2018). However, they also differ, as systematic reviews can exclude meta-analyses but all meta-analyses are found in systematic reviews and are often used for randomised controlled studies (Ahn & Kang, 2018). The eight stages of a systematic review are as follows: formulate the review question(s); define inclusion and exclusion criteria; develop search strategy and locate studies; select studies; extract data; assess study quality; and finally analyse and interpret data.

Specifically, this study utilised the PRISMA guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) by Liberati et al. (2009) to search for, and select relevant literature articles (the data collection). These guidelines were developed to ensure that researchers are transparent in reporting a systematic review.

Stage 1: Formulating the research question/s

The first stage required formulation of a research question/s. Although the approach to formulating a research question is similar to other research project approaches, in the current study a background check prior to development of the research question was conducted to ensure no recent review has been conducted in this topic area (Laher & Hassem, 2020; Uman, 2011). The phrase 'systematic review' was included to ensure identification of the review. Furthermore, in this first stage of this systematic review, research questions were defined and the review project title developed (Uman, 2011).

The research questions are:

1. What are the socio-emotional experiences of South Africans living with a disability?
2. What are the psychological theories attached to socio-emotional disability experiences?

The review project title is: A systematic literature review on the socio-emotional experiences of those living with a disability in South Africa.

Stage 2: Defining the inclusion and exclusion criteria

The second stage is essential for determining inclusion and exclusion criteria (Higgins & Green, 2011; Laher & Hassem, 2020; Uman, 2011). This step is critical to formulate as it provides a guiding tool in the development of search terms. Inclusion criteria are basic attributes that a research study must possess in order to be considered in the review (Laher & Hassem, 2020). Exclusion requirements are features of a research project that would automatically disqualify it from the review (Laher & Hassem, 2020). These criteria were developed before the study commenced, as recommended by Uman (2011). The method framework for identifying inclusion and exclusion criteria that was used for this research is the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation and Research type). This method framework is commonly used in systematic reviews of qualitative research, such as in the current study (Cooke et al., 2012; Laher & Hassem, 2020). Below are the key SPIDER components for this review:

Component	Definition
Sample	South African disabled people – all forms of disability
Phenomenon of Interest	Socio-emotional experiences
Design	Systematic literature review
Evaluation	Experiences (regarding their disability)
Research type	Qualitative

Description of inclusion criteria:

- Peer reviewed journals published by local or international authors on socio-emotional experiences of disability in a South African population. The study was interested in experiences of South African disabled individuals, however local and/or international authors who have studied socio-emotional experiences of South African disabled individuals were included in this review.
- Publication dates included in this review was over a twenty year period (2000 to 2021). This time frame was chosen as it is felt to be an important time in the area of disability studies since it is the time after the social model of disability emerged in the 1960s and 1970s by the British disability movement (Retief & Letsosa, 2018). Particular to the South African context, the social model forms a crucial role in policy making and in the formation of the Integrated National Disability Strategy (1997). Furthermore, the influence of the social model of disability in South Africa is evident in the 2002's Department of Labour's 'Code of Good Practice: Key Aspects on the Employment of People with Disabilities' (Retief & Letsosa, 2018). Therefore it is within this time frame where socio-emotional experiences of disability began to be researched and started to emerge more in the literature.
- Disabilities that form part of this study were all inclusive, including psycho-emotional (which constitutes mental and psychiatric illness); sensory (including deafness, blindness); physical; and neurological disabilities (including intellectual disability). Due to the novelty of this study, and with no systematic review that could

be located exploring the socio-emotional experiences of disabled South Africans, all types of disabilities ranging from born with and acquired were included.

- All types of studies (quantitative, qualitative, and theoretical) were included in this review because writings on the socio-emotional experiences of the disabled individual are still at an infancy stage in South Africa and there is scant literature in this field.
- The publications were all written in English to reduce language interpretation bias and considering that the population being reviewed use English as a medium of instruction.
- The publications' population included samples of 18 years and older. Adults were chosen for this study as this research emphasises the subjective experiences of disabled people, and as an adult one would be able to reflect on socio-emotional experiences. This study was exploratory in nature, thus most of the sample would have potentially made sense of their disability.

Description of exclusion criteria:

- Publications of studies with disabled participants less than 18 years of age. These publications were thought to be heavily reliant on caregivers' reported experiences of the disabled individuals they take care of, and not those experiences of the disabled themselves.

Stage 3: Developing the search strategy

The literature search was conducted in this stage (Uman, 2011). A search strategy was formulated (Laher & Hassem, 2020). This phase was broken down into two parts (Laher & Hassem, 2020):

1. Determining suitable search terms:

The search terms were created by breaking down the research issue into separate definitions. As recommended by Laher and Hassem (2020), Siddaway et al. (2019), as well as Uman (2011), search terms were made to be as broad as possible to ensure that

all appropriate records were found. Furthermore, alternate meanings or terms that characterise a concept, as well as synonyms and plural or singular words for a given phrase were considered (Laher & Hassem, 2020; Siddaway et al., 2019; Uman, 2011). For this study the following search terms were included: socio-emotional, feelings, inner experiences, attitudes, psychological experiences, disability, disabled, disabilities, impaired, impairment, psychological theories, psychic experiences, South Africa.

2. Determining which databases to use for the search of studies:

Additional to the creation of search words, the chosen databases for searching for literature allow for the use of Boolean functions to the search (Laher & Hassem, 2020). Boolean functions are words or special characters that can be used to remove or collate search phrases, such as AND, OR, and NOT (Laher & Hassem, 2020). The Boolean AND was used for all phrases or terms to be included in the results, such as feelings AND disability, hence it is narrow as phrases are used in combination. OR was used to get one of two terms or phrases in each result, such as feelings OR attitudes, which enlarged the results. NOT was used to exclude the second search term in each result. For example, NOT was used to exclude caregivers' and teachers' experiences regarding other's responsibility.

Critical to the search selection was choosing databases to conduct the search (Laher & Hassem, 2020). Databases can be specific to the field or multidisciplinary. More than two databases were selected, as suggested for a systematic review (Laher & Hassem, 2020). The databases that were chosen for this research study are shown in the table below:

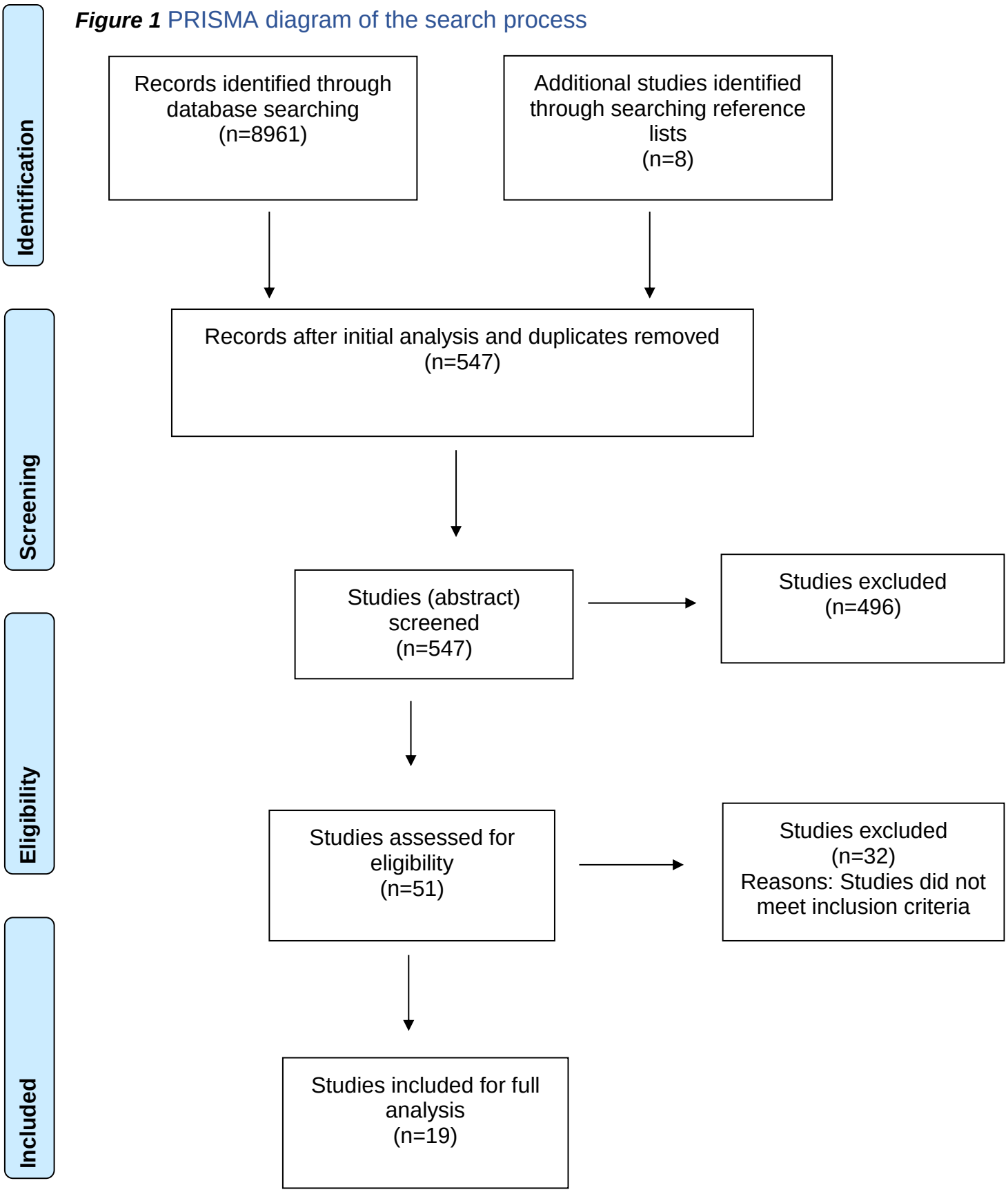
Database	**Reason for selection**
EBSCO Host: CINAHL, MEDLIN, Psychology and Behavioural sciences collection	Includes a multidisciplinary collection of literature globally. This is important as disability is a multidisciplinary concept.
Sabinet and Sabinet African journals	Covers a collection of full text journals that have their origins in, and pertaining to, Africa and Southern Africa. This was

	needed as this study was interested in studying South Africans' experiences.
PsychInfo	Focuses in psychology and other behavioural research globally.
PubMed	Contains general and mental health global literature.
Taylor & Francis	Contains multidisciplinary databases. This was chosen as many authors in disability publish with this organisation.

Stage 4: Screening the literature

This stage involved searching for studies through the use of the databases selected and search keywords, as discussed above. After the search, the titles and abstracts of the articles were screened using the inclusion and exclusion criteria discussed (Higgs & Green, 2011; Laher & Hassem, 2020; Uman, 2011). For this step, a referencing software, Zotero, was used, as suggested by Laher and Hassem (2020). This type of software allows one to save all of the database search results. A saved folder for each database's search was created and articles were saved systematically. The Ryyan software was used for screening of titles and abstracts of the articles searched. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram was utilised to ensure documentation of the detailed number of records identified or omitted in the search. A Microsoft Word document, as a record keeping log (see Appendix A), was used for each screening phase, and a spreadsheet was opened to record articles under each section. Below is a PRISMA diagram that was used (Figure 1). It is evident at what stages how many articles were found, screened, kept, or excluded.

Figure 1 PRISMA diagram of the search process



From: McKenzie et al. (2021, p. 5).

Furthermore, a bibliography was created in an alphabetical order, and any duplicates of articles were removed. Next, the screening of each article's title began. After exclusion of irrelevant titles, abstracts were screened with the inclusion and exclusion criteria in mind. Once all possible articles had been identified, full text articles were retrieved. This step included diligently reading articles and inspecting if inclusion and exclusion criteria were met, thereafter reasons for exclusion criteria were recorded. To reduce bias in the selection process, an inter-rater reliability method was employed as my research supervisor overlooked the process by being a collaborator, and was consulted on, at each stage (Uman, 2011).

Stage 5: Assessing for quality

Stage five involved assessment of the quality of all the articles to be reviewed (Laher & Hassem, 2020; Uman, 2011). The identified full text articles that met the inclusion criteria underwent the process of appraisal for their quality, so as to reduce bias. The aspects assessed for quality in this study included: assessing for relevance, design of the study, methodology (including sample, ethics, and procedure), analysis of data, and results reporting. Assessing the quality is important as it ensures that the methodology used in the studies is rigorous. The quality of qualitative articles was assessed using a tool for critical appraisal, called the Critical Appraisal Skills Programme (CASP) tool (Nadelson & Nadelson, 2014). The CASP was chosen to assess the quality of articles because it is succinct and concisely expressed, and effective in covering the areas needed for evidence of critical appraisal of qualitative studies. The qualitative CASP checklist uses ten subcategories of analysis (see Appendix B). The CASP does not sufficiently appraise quantitative and theoretical studies. Quantitative studies were appraised by an adapted version of the CASP of (see Appendix C). An adapted CASP consisting of six items was used to assess the quality of theoretical studies (Laher & Hassem, 2020) (see Appendix D).

Stage 6: Extracting data

Stage six entailed extraction of data guided by the research questions (Laher & Hassem, 2020; Uman, 2011). Extracted data was either descriptive (characteristics of the data) or analytical (data outcome). Descriptive data was grouped in a table format, the table includes information on authors, publication year, number of participants, age range, study designs, outcomes, and whether the study falls within the inclusion or exclusion criteria (Uman, 2011).

Stage 7: Data analysis

The analysis of the reviewed studies took a narrative approach of thematic synthesis (Kerrison et al., 2021; Lucas et al., 2021; Ryan et al., 2018). This method is an adaptation from thematic analysis (as described by e.g., Braun & Clarke, 2006) and is used for the purpose of secondary data synthesis. Thematic synthesis identifies and develops analytic themes in research data. This method was suitable for this study as it is commonly associated with synthesis of research outcomes of qualitative research. Additionally, this kind of synthesis offers accessible outcomes and good transparency, as the steps of the data analysis utilise a coding system that can be traced (Ryan et al., 2018). Thematic synthesis has three stages, and these were followed in this study. The first stage involved coding of the various studies' participants' experiences and perspectives. The second stage involved collating similar codes, which were grouped into 'descriptive themes' that describe and capture data patterns. The final stage entailed development of an analytic theme. The purpose of this final stage was to interpret meaning in relation to the research questions. Once these three stages were completed, the final analysis phase included comparing result sets, and overall understanding of socio-emotional experiences of disabled individuals were outlined (Ryan et al., 2018).

Stage 8: Writing up the findings

The last step of a systematic review is dissemination of findings. The findings of the proposed study were used to answer the research questions and to compile this research report. The next chapter will report on these findings.

Ethical considerations

Given that this study was a systematic review in nature, utilising already published papers which are readily available to the public and did not involve contact with human subjects, ethical permission was not necessary as the study involves no risk. However, in keeping with the University of the Witwatersrand's Human Research Ethical Committee (Non-Medical) guidelines, an ethics waiver form was completed and an ethical clearance certificate was granted (Appendix E). Specific ethical considerations that were taken into account include writing sensitively about what the articles reported on, as well as keeping in mind that articles reviewed are focused on a population that can be considered vulnerable and that have shared experiences that may be painful.

Chapter Four: Findings

The various databases that were searched (as discussed above) and additional reference list searches yielded a total of 8961 articles. After removal of duplicates and initial analysis, abstracts totalling to 547 were screened. The total number of articles that were excluded based on the abstracts amounted to 496. The articles that were assessed for eligibility by conducting quality assessment amounted to 51; of these articles 32 studies were excluded and 19 articles were identified as meeting the inclusion criterion of the study. Therefore, 19 studies were used for the review (see Figure 2) below:

Figure 2

Summary of results from included studies

Authors	**Title**	**Study Design**	**Sample** Size	Age range	Sample Gender	**Critical appraisal score**
Van der Heijden et al., (2019)	Additional Layers of Violence: The Intersections of Gender and Disability in the Violence Experiences of Women With Physical Disabilities in South Africa.	Qualitative	30	19 to 54	Female (100%)	8/10

Mavuso & Maharaj, (2017)	Reproductive health barriers facing men and women with disabilities in Durban, South Africa.	Qualitative	16	29 to 40 +	Male: 6 Female: 10	8/10
Naidoo & Ennion, (2019)	Barriers and facilitators to utilisation of rehabilitation services amongst persons with lower-limb amputations in a rural community in South Africa	Qualitative	11	23 to 80	Male: 3 Female: 8	7/10
Muthukrishna et al., (2009)	Gender and Disability: an intersectional analysis of experiences of ten disabled	Qualitative	9	22 to 35	Females	6/10

	women in Kwazulu-Natal					
McKinney & Amosun, (2020)	Impact of lived experiences of people with disabilities in the built environment in South Africa	Qualitative	4	38 to 50	Males: 3 Female: 1	10/10
Swartz et al., (2020)	They don't understand that we also exist": South African participants in competitive disability sport and the politics of identity	Qualitative	22	38 to 50	Male: 16 Female: 6	9/10
Bantjes et al., (2019)	Troubling stereotypes: South African elite disability athletes and the paradox	Qualitative	22	18 to 67	Male: 17 Female: 5	8/10

	of (self-)representation					
Roux & Burnett, (2011)	The extent to which students with disabilities are included in elite sport at higher education institutions	Qualitative	4	21 to 27	Male: 3 Female: 1	8/10
Laas (2012)	Journey through the Trials and Triumphs of Disability	Qualitative	1	18+	Female	9/10
Swartz & Greyling, 2011	Participation in higher education: experiences of students with disabilities	Qualitative	10	18+	Male: 2 Female: 8	8/10
Brooke-Summer	Perceptions of psychosocial	Qualitative	18	18+	Not mentione	8/10

et al., (2014)	disability amongst psychiatric service users and caregivers in South Africa				d	
DE Klerk & Ampousah, (2003)	The physically disabled woman's experience of self	Qualitative	40	21 to 60	Females	8/10
Thurston et al.,20200	Sex, support and society: a journey to reclaiming sexuality for individuals living with paraplegia in Cape Town, South Africa	Qualitative	10	18 to 48	Male: 8 Females: 2	9/10
Watermeyer (2009)	Claiming loss in disability	Theoretical	n/a	n/a	none	6/6

Lourens (2018)	Driving in unheard silence and the politics of shutting up.	Theoretical	Mother-infant dyads (n=674)	18+	n/a	5/6
Mutanga (2013)	I am a university student, not a disabled student": Conceptualising Identity and social Justice In south African higher education through the Capabilities approach lens	Theoretical	1	18+	Female	4/6
Watermeyer et al., (2019)	Navigating the Relational Psychic Economy of Disability: The Case of M	Theoretical	n/a	18+	n/a	6/6

Trani et al., (2020)	. Stigma of persons with disabilities in South Africa: Uncovering pathways from discrimination to depression and low self-esteem	Quantitative	196	18 to 89	Males: 76 Females: 120	12/12
Neille (2015)	Beyond physical access: a qualitative analysis into the	Qualitative	30	19 to 83	Male: 15 Female: 15	10/10

Over the 20-year period (2000 – 2020), 19 studies provided insights into socio-emotional experiences of South Africans living with a disability, as shown in Figure 1. Qualitative studies formed the majority of the studies, specifically 14 (73.7%), followed by theoretical studies, four (21.1%), and finally, one quantitative study (5.3 %). Population age included in the studies is between 18 to 89 years. Studies that were based on 18+ age sample were seven (36.8%), studies that were based on age group between 18 to 35 were two (10.5%), studies based on 35 to 50 were three (15.8%), and 50+ age sampled amounted to six papers (31.6%.). One article (5.3 %) was a theoretical paper on psychological theories related to socio-emotional experiences of disability, and thus did not have participants.

Five studies (26,3 %) were conducted in the Western Cape Province, four (21.1%) were conducted in Kwazulu-Natal Province, one (5.3%) from North West Province, one (5.3%)

from Mpumalanga Province, four (21.1%) from Gauteng, one (5.3%) from Free State Province, and three (15.8%) were from across the country's provinces.

Of the 19 articles reviewed consisting of quantitative, qualitative, and theoretical studies, descriptive and analytic themes were produced in the synthesis. The results identified thirteen descriptive themes; these descriptive themes were further analysed to construct four analytical themes.

Descriptive themes (findings of studies)

Theme One: Positive experiences

This theme addresses the extent to which those living with a disability have reported experiencing positive emotions regarding their disabilities. Some findings reported that people living with a disability experienced a feeling of proficiency and accomplishment when participating in competitive disability sport (Bantjes et al., 2019). Some participants further noted that they felt like they were capable of doing something with their lives. One participant said, *"then I found out that blind people also can do something with their lives"* (p. 6), which was accompanied by a sense of self-worth, self-value, confidence, feeling good about themselves, and pride (Bantjes et al., 2019; De Klerk & Ampousah, 2003). Participants in the various articles also felt that they had an opportunity to represent themselves as strong. Associated feelings were of freedom, hope and encouragement, empowerment, contentment, feeling connected to other people, as well as a sense of thankfulness about their own self (Bantjes et al., 2019; McKinney & Amosun, 2020; Swartz et al., 2018).

Theme Two: Negotiating identity

Participants across the reviewed articles found themselves in a paradox of feeling 'normal' but different. They reported experiencing feelings of rethinking their own ideas regarding their disability, as they had initially thought that they could not do anything because of their disability. At the same time, they felt that they were dismissed, unacknowledged by abled bodied people, and felt that their disability defined them

(Bantjes et al., 2019). Some participants reported that when their identity was challenged in social interactions, they experienced themselves as outside of their 'illness'. A participant said, *"we're not disabled here [on the sports field]. I forget the disability"* (Bantjes et al., 2009, p. 8). However, they experienced themselves as different, as well as being treated differently to others, which left them feeling like they have internalised society's oppression towards disability (Lourens, 2018). Thus, they are left having to decide how they see themselves which impacts their identity and self-concept (Muthukrishna et al., 2009). This leaves people with a disability in a continuous grapple between their disabled body and their overall, more integrated identity (Watermeyer et al., 2019), which can leave them feeling different and disoriented (Lourens, 2018).

Theme Three: Need to motivate others

Across the articles reviewed, there was often a strong sense of those living with a disability to endure their experiences, regardless of the challenges they face to motivate other disabled people, or to prove that they can be successful despite their disability (Bantjes et al, 2019; McKinney & Amosun, 2020; Muthukrishna et al., 2009; Swartz et al., 2018). Participants felt a deep responsibility to make an emotional impact on others and be an example to those who find themselves in similar situations (Laas, 2012). A participant said, *"it [disability] calls for more awareness – we have to keep on doing what we're doing and making people aware and calling government to account"* (McKinney & Amosun, 2020, p. 7).

Theme Four: The need for belonging

There were many instances in which participants raised that they found themselves in situations where they felt like they did not belong because of their disability (Lourens, 2018). *"Every stare, every inaccessible look, every transport crisis contains the visceral message that 'I do not belong in this world; that this world is not my home'"* (p. 6). These experiences were reported in stares that people gave various participants, the inability to access certain spaces, and in every crisis that the disabled person finds themself in (Lourens, 2018). Participants felt a sense of belonging when they were able to access services, and when they were able to interact with the environment, which helped them

build a sense of belonging and inclusion in the society (McKinney & Amosun, 2020; Swartz et al., 2018). Participants felt most connected to a larger community through meeting other people with disabilities: *"through sport they met other people with disabilities and felt connected to a larger community"* (Swartz et al., 2018, p. 5).

Theme Five: The paradox of dependence and independence

Some participants experienced feelings of loss which are associated with the experiences of exclusion by, and dependency on, abled-bodied people (Watermeyer et al., 2019). A participant who became disabled after a motor vehicle accident reported that he found himself dependent on the same people (able-bodied) that stigmatise him (Watermeyer et al., 2019). This experience presents a unique situation in which he has to negotiate his dependency on those who 'attack' him – able-bodied people. Most participants had a desire for independency, and when this was not accessible it felt that they were denied autonomy; some felt a lack of control, or even feelings of worthlessness, being pitied or treated as charity cases (Mavuso & Maharai, 2017; McKinney & Amosun, 2020; Muthukrishna et al., 2009; Roux & Burnett, 2011; Visagie & Swartz, 2018; Watermeyer et al., 2019). These experiences left participants in a constant awareness of their needs, feeling like an inconvenience, or drowning in offers of help because of their disability (Brooke-Summer, 2014; Lourens, 2018; McKinney & Amosun, 2020). *"The participants had to maintain a constant awareness of their needs and had become mindful of checking out the environment where possible"* (McKinney & Amosun, 2020, p. 6).

Theme Six: Negative emotions

There are varying negative emotions experienced by disabled people that were highlighted across the articles. The most negative emotions that were experienced were those of frustrations, anger, fear, humiliation, worthlessness, embarrassment, self-consciousness, discomfort/urge to hide, being dismissed, invisible, unacknowledged, and humiliated (Bantjes et al., 2019; Laas, 2012; Lourens, 2018; Muthukrishna et al., 2009; Roux & Burnett, 2011; Swartz et al., 2018; van der Heijden et al., 2019; Watermeyer et al., 2019). For example, *"the participants experienced a sense of being defeated by the environment. They also felt rejected by society and ignored by the government, which*

intensified their sense of helplessness" (McKinney & Amosun, 2020, p. 6). Thus, an overall sense that most of the participants shared regarding their experiences with a disability include stigma, negative impact on their emotional wellbeing (Brooke-Summer et al., 2014), diminished self-esteem and depression (Thurston et al., 2020; Trani et al., 2020), feeling excluded, introverted and not normal (rejection) (Swartz et al., 2018), as well as feeling judged (Mavuso & Maharai, 2017). There were also feelings of fear related to discrimination/neglected and denied rights and access to services (Laas, 2012; Mavuso & Maharai, 2017; Mckinney & Amosun, 2020; Muthukrishna et al., 2009; Neille, 2015). When participants could not access certain services, feelings of helplessness, worry, anxiety, stress, short temper, and despondence were evoked (Brooke-Summer et al., 2014; Lourens, 2018; McKinney & Amosun, 2020).

Theme Seven: Constant fear of discrimination

Most participants spoke of a common experience where they have been dismissed or unacknowledged because of their disability (Bantjes et al., 2019). Muthukrishna et al. (2009) reported that women with a disability suffer from discriminatory practices because of their gender. As a result, these participants were left feeling unhappy: *"most people do not accept us as human beings. Such prejudices make one unhappy"* (p. 6). Some participants reported feeling discriminated against within their family context, which made them feel isolated and lonely (Muthukrishna, 2009). Furthermore, the fear of discrimination prevents them from utilising certain services, as they feel that certain services are not made with disabled people in mind (Mavuso, 2017; Muthukrishna, 2009). Trani et al. (2020) found that those living with a disability and the experience of stigma was associated with depression and low- self-esteem.

Theme Eight: 'Shutting up'

Although living with a disability means that some participants feel a need to constantly self-advocate for themselves (Swartz & Greyling, 2011), most times participants feel that they have to be silent (Lourens, 2018; Muthukrishna et al., 2009). This is because they found themselves in a situation where the person that is helping them is the very same person that seems to 'attack' them (Watermeyer et al., 2019). This leaves people with a

disability feeling like they are caged, betrayed, or helpless (Lourens, 2018). Some participants reported feeling introverted: *"I was very introverted – maybe more so because of my disability. I could not look people in the face when I talked to them. They did not understand and thought I was talking to somebody behind them"* (Roux & Burnett, 2011, p. 7). A disabled woman described her experience in a hospital where she was too afraid to speak as the doctors and nurses made decisions for her regarding taking care of her child, because of her disability: *"the worst part was when the social worker, doctors, nurses decided to give up my child for adoption. The social worker gave me a letter to take to the hospital when I went to deliver the baby. No one had asked my opinion about giving up the baby for adoption, and I was too afraid to say anything"* (Muthukrishna et al., 2009, p. 13).

Theme Nine: Vulnerable

People living with a disability also reported feeling vulnerable. They reported feeling like they are being used by partners or family members relating to the grant money they are receiving. They report different treatment when they receive money to when they do not have money (Neille, 2015). They also experienced forms of violence from their families or partners (Neille, 2015). They often find themselves as victims of sexual abuse and exploitation, and in relationships they often feel used and taken advantage of (Muthukrishna et al., 2009). Van der Heijden et al. (2019) also found that disabled women experience financial abuse due to the Disability Grant they receive. Furthermore, most disabled women participants reported that their sexual experiences were coercive and non-consensual. Van der Heijden et al. (2019) argued that these disabled women are at risk of double violence, because they are doubly marginalised through their gender and ability.

Theme Ten: Use of humour as security in relationships

Some participants reported that they resorted to humour to secure relationships that are areas of support (Watermeyer et al., 2019). This includes, making a joke or fun of their situation to make the other feel comfortable: *"especially in my situation, I'm even making a joke or fun of myself so that they can feel comfortable to joke with me"* (p. 11). Other

times, participants reported relying on humour when lack of access is encountered in busy places: *"in busy shops, I have often resorted to humour when I could not move through an aisle and I have to ask people to move their trolleys"* (Laas, 2012, p. 4). Additionally, participants across the studies reviewed did not allow themselves to be sensitive to what others say to them with reference to their disability. This action was done to provide those around them permission to position the disabled person in the identity that the able-bodied wish. Furthermore, a person with a disability felt the pressure to 'break the ice' with their colleagues regarding their disability, which afforded them a reassuring role in relationships, by being sensitive to others' needs and feelings, as well as by denying their own feelings (Watermeyer et al., 2019).

Theme Eleven: Feeling good about oneself

When women were interviewed regarding their disabled selves, it was found that some women feel good about themselves, experiencing themselves as capable, and as having the same feelings as able bodied people: *"I feel great and happy about myself"* (De Klerk & Ampousah, 2003, p. 4). Furthermore, some participants reported that they feel satisfied in their disability, and furthermore, that beautiful clothes make them feel good about themselves (De Klerk & Ampousah, 2003). Additionally, some participants felt thankful and proud about their disability (Swartz et al., 2018).

Theme Twelve: Working twice as much as able-bodied people

Another theme that emerged is the work that the disabled participants put in to be successful is reportedly twice as much as able-bodied others. A woman describing her own experiences with a disability and motherhood reported that it was more than she could achieve, thus she mostly relied on her families and friends: *"my expectations of myself as a mother are frequently still more than I am able to achieve. Even though I understand that I have limits, I have to rely on my family and friends to help me to carry out normal family activities"* (Laas, 2012, p. 4). Furthermore, she would feel overwhelmed by fear, when she realised the work took much longer than she had expected. Participants also reported that they had worked hard because of their disabilities so that they could be where they are (McKinney & Amosun, 2020). Other participants mentioned that it is hard

to use resources that they need such as rehabilitation due to inaccessible transport and extremely high transport costs (Naidoo & Union, 2019).

Theme Thirteen: Acceptance

Acceptance of a disability was also a major theme found across the 19 articles reviewed. Participants reported that they have achieved an integrated self, including their disability as part of themselves, and as having accomplished something. Feeling accomplished makes acceptance of their disability possible, and makes participants feel capable and unashamed. The facilitator to acceptance of disability is reportedly success in interacting with the environment, which serves to offer different perspectives from what they know, that they have been socialized into society, that they are not unable, as well as in finding meaning in their disability (Bantjes et al., 2019; Swartz et al., 2018). Not only people living with a disability come to accept themselves, but it feels important to be accepted like an able-bodied person (Roux & Burnett, 2011). To some participants, acceptance of their disability played a key role in overcoming difficulties they experienced in relationships (Thurston et al., 2020). Acceptance of a disability also serves as a coping mechanism and a way to negotiate living with a disability: *"so, it was just that situation and that change of life now. You have to accept that you can't change it. It's changed already, so you have to deal with it and you have to live that"* (Watermeyer et al., 2019, p. 10). Some participants also reported that they feel that society fails them often, viewing them as the same as able-bodied people, which leaves them with feelings of being dismissed and unacknowledged (MuthuKrishna et al., 2009).

Analytical themes (synthesis of findings)

Four analytical themes were developed and are presented below.

1. *Experiences of various emotions*

Disabled people feel different emotions regarding their disability. Most participants in the reviewed articles reported experiencing positive emotions when they are participating in their environments. Participants feel that opportunities they receive while participating in various activities helps them see that they can do something with their life and are able

to claim their own representations of themselves, which makes them feel proud and connected to other people (Bantjes et al., 2019; McKinney & Amosun, 2020; Swartz et al., 2018). Participating in their environment also affords them opportunities to rethink their own ideas regarding their disability and negotiate their own identity (Bantjes et al., 2019). These perspectives indicate that it is crucial that disabled people are given opportunities to participate, be part of, and represent themselves in society, as it is a place where they find meaning, and can experience themselves as capable despite various disability-related difficulties they may face.

In contrast, disabled people also report experiencing negative emotions. Most participants experience frustration, anger, and humiliation. These feelings are brought up in situations where participants feel discriminated against due to their disability, or they were unable to access certain services within an environment, as well as able bodied people's attitudes regarding their disability. As a result, disabled people find themselves with feelings of helplessness, anxiety, and despondency (Brooke-Summer et al., 2014; Lourens, 2018; McKinney & Amosun, 2020). This indicates that just as disabled people experience positive emotions when they are given opportunities to participate in their environments, they also experience negative emotions when their environments are inaccessible, discriminative, and stigmatising. It is crucial for people to be sensitive to their attitudes regarding disabled people and to provide disabled people with opportunities to represent themselves.

2. Emotional needs in people with disabilities

Many studies reviewed include disabled people's needs, including a need to belong, a need to motivate others, and a need for independence. Participants feel that they constantly find themselves in situations where they feel different and do not belong. These needs are mostly mediated by people, from experiences of people staring at various participants, inability to access certain spaces, and every crisis the disabled person is in. In contrast, a sense of belonging is achieved through positive interactions with the environment and access to services (McKinney & Amosun, 2020; Swartz et al., 2018). Participants also highlight the desire to be independent. However, this sometimes feels

unattainable due to inaccessible environments or services in certain cases. When participants find themselves in situations that feel difficult, they feel a strong sense to endure their experiences, to motivate other disabled people, and to prove that they can be successful. Thus, there is a deep sense of responsibility to make an emotional impact on others and be an example. This suggests that disabled people are aware of their needs, it is the environment that hinders these needs due to inaccessible services, as well as people's reactions to the disabled body.

3. Disabled people find themselves in unsafe environments

It is not an uncommon experience that disabled people face, that of being dismissed or unacknowledged, particularly women with disabilities (Bantjes et al., 2019). Most people with a disability report feeling discriminated against, by their family and from certain services (MuthuKrishna et al., 2009). Some participants find themselves in a paradox of constantly needing to self-advocate and feeling that they must be quiet (Lourens, 2018). Furthermore, disabled people feel vulnerable in their environments. There are instances where they feel 'used' and mistreated by family or their partners (MuthuKrishna et al., 2009). They report experiencing themselves as victims of sexual assault and exploitation and feel taken advantage of in relationships. These experiences suggest that disabled people not only face discrimination from the environment, but also from people that are around them. Disabled people also find themselves at a vulnerable place within their relationships, and are at risk of both physical, financial, and sexual abuse (Van der Heijden et al., 2019).

4. Taking back control

Participants take back control of their disability through acceptance of their position, use of humour, and working hard (Watermeyer et al., 2019). Across the nineteen articles reviewed, acceptance of disability was a major theme. Participants reported that acceptance of their disability was achieved through feeling accomplished (Bantjes et al., 2019; Swartz et al., 2018). They experience success in interacting with the environment, which serves to offer different perspectives from what they know. Thus, receiving the message from their environment that they are capable. Disabled people not only accept

their disability, but they also desire to be accepted like an able-bodied person. It is acceptance that serves as a coping mechanism and as a way to negotiate living with a disability (MuthuKrishna et al., 2009). It feels significant that disabled people need to be viewed by society as the same as able-bodied people.

Disabled people also take back some control by putting in the work to ensure that they are successful, although their effort is reported as twice as much as able-bodied people (McKinney & Amosun, 2020; Swartz et al., 2018). They work hard because of their disability so that they could be where they are, although participants mentioned that it is hard to use resources, and costs are high. Furthermore, some participants report that they manage using humour to secure relationships that are supportive, or when lack of access is encountered, although this may sometimes look like making fun of themselves. Additionally, participants across the studies reviewed tried to not be sensitive to what others say to them with reference to their disability (Watermeyer et al., 2019). This means that although disabled people face many challenges, they get to a place where they accept their disabled body and make means to navigate their difficulties. It is unfortunate that they put in more work than able-bodied people and seem to not only manage their own feelings but those of the able-bodied people as well (Watermeyer et al., 2019).

With regards to psychological theories that are attached to socio-emotional experiences of disabled people. Only one study critiqued psychological theory. It was found in this study that there is no specific theory that is attached to socio-emotional experiences. However, Watermeyer (2009) argued that within the medical and rehabilitation approaches of disability, disability is largely viewed as with psychic experience of loss. Thus, the public discourse about persons with disability remains deeply attached to the construct of incomplete and lacking life. Watermeyer (2009) reported that a number of academic papers have been devoted to the concept of disability adjustment which draws on models of bereavement. Furthermore, the experience of disability is viewed as a concept of adjustment as well as the process of overcoming one's perceived reality, which enables one to develop a new mode of living.

In contrast, this concept is often rejected by the disability movement, particularly the social perspective model. The disability movement's rejection of loss is rooted in the idea that disabled people are unjustly treated as objects of social control. Further, it is often the case that representation of disabled people in the media fails to capture the full range of experiences and individuals with a disability. Instead, the images of people with disabilities are often portrayed as failures and hopeless.

It was further noted from the review studies that there was no trending psychological research that was often referred to with regards to the experiences of disabled people. However, some researchers briefly mention experiences relating to the social model or experiences of disabled people would be socially or environmentally based.

Conclusion

The review found that most studies were based on socio-emotional experiences of disabled people when interacting with their environment, thus focusing on the social part of their experiences, and not necessarily on their own subjective emotional aspects of their disability. When interacting with the environment, both positive and negative emotions were highlighted in the studies. It is clear that the experiences of disabled people are closely related to their experience of their disability within their contexts. Disabled people's experiences suggest that it is crucial for disabled people to be given equal opportunities to participate, have access to services, and be part of their environment.

Chapter 5: Discussion and Conclusion

The primary goal of the current systematic review was to identify, appraise and thematically synthesise existing and available literature on socio-emotional experiences of disabled South African people regarding their disability. This was to gain in-depth knowledge of personal socio-emotional experiences as reported by disabled people in South Africa. Furthermore, the research aimed to identify psychological theories that are attached to socio-emotional experiences of disabled people, as well as identify gaps in literature and generate recommendations where needed regarding future research.

This research review has shown that over a 20-year period from 19 studies that were included in this review, 13 descriptive themes emerged which were further analysed to four analytic themes. The table below shows both the descriptive and analytical themes that were found in this research.

DESCRIPTIVE THEMES:	**ANALYTIC THEMES**
Descriptive Themes	
Positive experiences	*Experiences of various emotions*
Negotiating identity	*Emotional needs in people with disabilities*
Need to motivate others	Disabled people find themselves in unsafe environments
Need to be belonging	Taking back control
The paradox of dependence and independence	

Negative emotions	
Constant fear of discrimination	
Shutting up	
Vulnerable	
The use of humour as a security to secure relationships	
Feeling good about oneself	
Working twice as much as abled bodied	
Acceptance	

The discussion will centre mostly on analytical themes as they allow the study results to 'go beyond' findings of the primary studies and generate new knowledge (Thomas & Harden, 2008).

Experiences of various emotions

Central to the experiences of disabled people, disabled people feel different emotions regarding their disability. In the reviewed studies, most participants reported feeling positive emotions when participating in their environment. These participation aids them to see that they can do something with their life and are able to claim their own representations of themselves, which makes them feel proud and connected to other people. A participant mentioned *"then I found out that blind people also can do something with their lives"* (Bantjies, 2018, p. 6). Furthermore, they saw themselves as capable despite challenges they may face related to their disability. These experiences show that disabled people have experienced limiting beliefs regarding their disability which is

society based, hence filled with pride when they can. These experiences are consistent with the social model, which addresses contextual issues that disadvantaged disabled people (Haegele & Hodge, 2016; Shakespeare, 1993, 2018; Watermeyer, 2013, 2016; Watermeyer & Gorgens, 2013), imposing barriers to accessibility and inclusion (Shneinder, 2006; Watermeyer, 2014). Watermeyer (2014) reported that psychological (emotional) realm of disabled people has been viewed as a diversion from the discrimination and prejudices that disabled people are facing, which has been found in this research that very little information was found regarding emotional expression of disabled people outside interaction with their environment, supporting Watermeyer's (2014) argument that disabled people emotional life is constrained by social barriers (Watermeyer, 2014). From the literature review, only one study by (Schnitzler, 2020) reported that disabled people experience different emotions, which can be both positive and negative.

In contrast, disabled people also report experiences of negative emotions. These emotions included frustrations, anger, and humiliation. These feelings were brought up when participants felt discriminated against or in interacting with inaccessible environments, which brought feelings of hopelessness, anxiety and despondency. The development of these feelings was primarily based on the interaction with the environment. For example, *"the participants experienced a sense of being defeated by the environment. They also felt rejected by society and ignored by the government, which intensified their sense of helplessness"* from an inaccessible environment (McKinney & Amosun, 2020, p. 6). Furthermore, it was found that stigma was directly linked to negative emotions such as depression and low self – esteem (Trani et al., 2020). Studies have shown that there is a strong relationship between stigma and negative psychological consequences (Morwane & Dada, 2021; Watermeyer, 2016). Furthermore, it has been reported by Swartz et al. (2020) that discrimination that disabled people face is alarming, even in institutions that are keen for transformation and have policies in place. It is noted that literature is consistent in that these psychological experiences are largely influenced by stigma projected onto disabled people (Shakespeare, 1993, 2018; Swartz et al., 2020; Trani et al., 2020; Watermeyer, 2014, 2016, 2017).

Emotional experiences of disabled people seem to be secondary emotion from their experiences when interacting with the environment, as it was noted that these feelings were mainly heavily influenced by the response from the environment or from people and were not subjective feelings of one's own disability. These experiences are significantly linked to the social part of experiences of disability, which is consistent with the disability social model. These findings suggests that feelings of disabled people are still dominated by their environment, and the psychological effects faced are due to discrimination and prejudices based on disability (Watermeyer, 2016). Thus, these emotional experiences are dire and even though they are not mirrored in full, as they are covered by social experiences (Watermeyer, 2016). Furthermore, this social harm, which have been shown extensively from this review, do affect disabled people's identity (Morwane & Dada, 2021), which then collate as emotional experiences of disabled people, regarding their disability at a personal level, however, own subjective experiences with disability apart from the environment were not prominent from this review. These findings confirm the controversies that surround psychology theory regarding disabilities (Watermeyer & Swartz, 2016). Thus, due to discrimination people with disabilities are left unable to talk about their emotional experiences as it feels individuals do not have resources to experience their emotions due to feeling like a burden because of their disability which results in a need to eradicate their feelings (Watermeyer, 2017; Watermeyer et al., 2019). It can be hypothesized from the findings that disabled people are unable to talk about their subjective experiences of their disability because they lack resources to do so due to discrimination they face already. It is not surprising that disability studies place focus on materialistic aspects and have paid little attention to psychological experiences that exist (Watermeyer, 2016) because the material aspect (discrimination, lack of access, prejudices, and lack of services) of disabled people is alarming, and has harmful psychological effects (Rule & Modipa, 2012; Watermeyer, 2016). Furthermore, the prevalence of these stereotypes can leave people with disabilities feeling isolated and reluctant to acknowledge their own negative experiences such as loss (Watermeyer, 2014), thus preventing them from developing a deeper understanding of themselves. Expressing these feelings of sadness or loss may seem threatening because of expecting to be judged by default through the lens of the disability stereotype (Watermeyer, 2014).

Emotional needs in people with disabilities

The experiences of disabled people also include discovering their needs. These needs include the need to belong, the need to motivate others and the need for independence. Most individuals found themselves in situations where they feel 'different' and not belonging. Swartz et al. (2020) also reported a feeling of being different and sharing these differences felt like it was intolerable. *"Every stare, every inaccessible book, every transport crisis contains the visceral message that 'I do not belong in this world; that this world is not my home'"* (Lourens, 2018, p. 6). Discovering these needs were often mediated by people, from stares, inability to access environment, crisis the disabled person may find oneself in. Equally, disabled people found themselves needing to be independent, although it felt unattainable due to inaccessible, unavailable services or uncontested assistance. Furthermore, disabled people felt that they needed to be strong to motivate others, regardless of the difficult experiences. These experiences of needs discovery are in line with the social model of disability, as it is still the social experience and are mediated by people (which is still the environment) that the disabled person finds themselves in. Subjectively, the discovery of their needs is brought out by the set-up of the environment, such as mentioned above of people stares, or in a moment of crisis where an individual with a disability realises the inaccessibility of the environment, then realise they need some assistance to interact with the environment. This is also consistent with Shakespeare (1993) who argued that it is true that people with disabilities are often subjected to ridicule and hostility when they enter the public realm. Furthermore, harassment is a common concern for both men and women who are disabled. Swartz et al. (2020), an author who shared one of the stories of attending an emergency meeting, which left him feeling excluded and embarrassed for raising his concerns, as those who were they answered with ignorance. Shakespeare (2018) concurred that there are many cases where people with learning difficulties were exploited for their welfare benefits. These individuals were then subjected to various violent acts, usually carried out by non-disabled people.

Disabled people find themselves in unsafe environments

Disabled people also find themselves in unsafe environments, where they are dismissed or unacknowledged, particularly women with disabilities. These findings are consistent with previous research, which has indicated that women with disabilities face 'double oppression', that of being a woman and that of being a person with a disability (Shakespeare, 1993; Swartz et al., 2018). Disabled people reported feeling discriminated against, from their family members to the society. This leaves them in a paradox of advocating for themselves as well as being silent. It has been argued that feeling silenced is a common phenomenon experienced by disabled people (Neille, 2020; Shakespeare, 2018; Swartz et al, 2020; Watermeyer, 2017). There are also instances where they feel used and mistreated by their partners or families. Some reports finding themselves as victims of sexual assault and exploitation. Although these experiences of disabled people especially women bring out different emotional experiences, the primary experience is still emphasised on the environmental interaction. The discrimination is coming from family and the society, which is still significantly social experiences. As a result, individual subjective experiences are severely dominated by the social experiences of a disability. These findings are consistent with previous research, in that women with physical disabilities experience double oppression (Majiet & Africa, 2015; Mehrotra, 2006). Majiet and Africa (2015) further reported that experiences of women with disabilities triples if they are from a disabling world (Mehrotra, 2006). Furthermore, compared to able-bodied women, disabled women and girls face various forms of human rights abuses, such as exploitation and abuse as well as various forms of discrimination because of their social isolation and dependency (Grobbelaar-du Plessis, 2007).

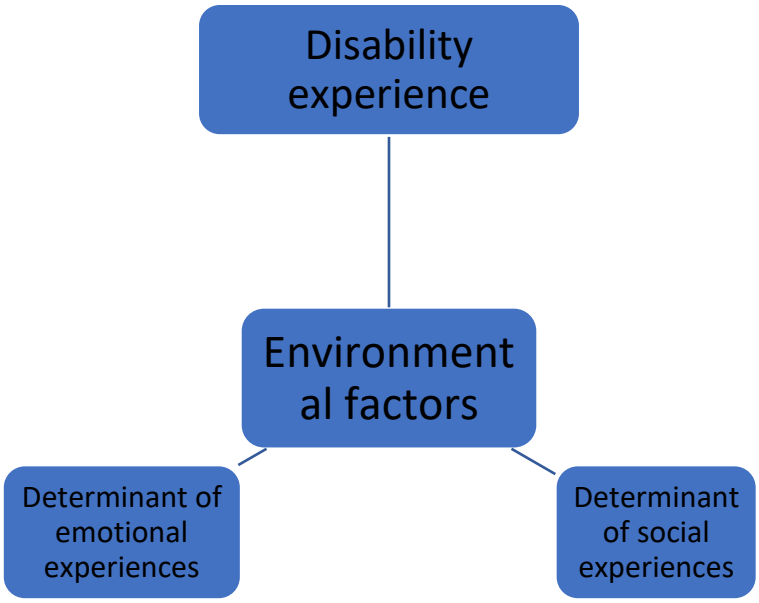
Taking back control

Lastly, participants felt that they take back control through acceptance of their position, employing humour and working hard. It is well documented that disabled people do not only manage their own feelings, but manage those who are non-disabled, and sometimes can deny their own feelings (Shakespeare, 1993; Shakespeare, 2018; Watermeyer, 2014). In this review, it was found that disabled people's acceptance was a major theme, which was achieved through feeling accomplished, experiencing success in interaction

with the environment which offers a different perspective from what is known. As they have been socialised into that they are not able. Acceptance comes with finding meaning of their disability as opportunities to employ their physical disabilities (Bantjes et al., 2019; Swartz et al., 2018). Not only people living with a disability come to accept themselves, but it feels important to be accepted like an 'able-bodied' (Roux & Burnett, 2011). To some participants, acceptance played a key role in overcoming difficulties they experienced in relationships (Thurston et al., 2020). Acceptance of a disability also serves as a coping mechanism and a way to negotiate living with a disability: *"So, it was just that situation and that change of life now. You have to accept that you can't change it. It's changed already, so you have to deal with it and you have to live that"* (Watermeyer et al., 2019, p. 10). It is noted that acceptance of disability is hugely accounted for acquired disability. Shakespeare (2018) argued that the experience of disability differs due to the nature of disability. A person who is born with a disability and a person who acquired disability at a later stage, process these experiences differently. Furthermore, Watermeyer (2014) found that in psychotherapy with disabled people, loss was a major theme. Furthermore, participants when they've accepted their experiences with a disability, there is a desire to be accepted by people. Sometimes, it means that their effort is twice as hard, they put in the work to ensure that they are successful.

Proposed model of understanding socio-emotional experiences

Figure 3 below is the proposed model to consider when understanding the socio-emotional experiences of disabled people. As shown in the figure, environmental factors are central to it as it determines the socio-emotional experiences which are largely related to social interactions and not subjective emotional experiences regarding their own disability as discussed above.



Limitations of the study

Due to the nature of the method of this research which is a systematic review, the reader should bear in mind that there are various methods that are used to collect data in systematic review, and depending on the method utilized, results might slightly vary. However, the protocol followed as recommended by Uman (2011), ensures that the results obtained by this review are reliable and replicable although there is slight variation as well as a limited ability to provide sufficient information from the included studies. Furthermore, there was one study which could not be retrieved. Another limitation of this study is the inability to generalize findings beyond South African context.

Recommendations

The finding of this study suggests that more than half of the studies reviewed did not mention emotional experiences of disability without attributing these experiences to environmental factors. Shakespeare (1993) and Watermeyer (2016) suggested that the social model excludes the emotional aspects of disability, in order to avoid confirming hateful ideas regarding disabled people. Majority of experiences are when disabled

people are interacting with their environment, and little is mentioned regarding disability as a subjective experience before limiting and stigmatising contextual factors. Resulting in the various experiences regarding living with a disability are evoked when individual with a disability is experiencing discrimination, when they face inaccessible environments or when people in the environment make them uncomfortable.

As suggested, emotional experiences of disabled people regarding their disability are still at an infant stage, and the majority of studies do not cover those experiences exclusively. As a result, experiences that were found in this review were mainly social, lacking the emotional subjective aspect experience of one's disability. Although some studies briefly mention it, it is not studied in detail to offer a range of feelings towards one's own disability. These experiences are in accordance with the dominating social model of disability, which emphasis is on environmental factors that excludes disabled people. Thus, confirming that the social model has failed to account for emotional facets of disability and highlighting the lack of the social model in excluding emotional experiences, even though they exist. To understand experiences of disabled people in a holistic manner, it is suggested that future research should focus on subjective emotional experiences of disability, to shed light on how these experiences interact with the environment factors and impact the experiences of those living with a disability in South Africa. There were very few instances where participants will refer to their own feelings regarding their disability, as separate from environmental or societal factors. Thus, it would be interesting to look at disability experiences from a subjective kind of view and compare these experiences with the well-developed experiences from a social point of view.

Further work that would be interesting to establish is distinguishing and comparing experiences of disability from the types of disabilities such as congenital and acquired disability, societal factors such as ethnic groups or socio-emotional factors.

Conclusion

The chapter will conclude the research by summarising the main findings in relation to the aims of the research and research questions, as well as the contribution and the value thereof. This chapter will also review the limitations of this research as well as propose future research opportunities.

The current research primary goal was to systematically review, identify, appraise and thematically synthesise existing and available literature on socio-emotional experiences of disabled South African people regarding their disability. The key findings of this research was that disabled people experience various emotions regarding their disabilities. Thirteen themes were found as descriptive themes and further analysed to four analytical themes which are: development of various emotions inclusive of positive and negative emotions, disabled people's discovery of needs, disable people find themselves in unsafe environments, and lastly, taking back control.

Findings of this research demonstrated that the experiences of disabled people regarding their disability is heavily influenced by their environment. This is in line with the disability social model, which describes the environment as oppressive and attributed the stigma received by disabled people as problematic. Little attention has been dedicated to subjective experiences of disabled people apart from their environment. Hence it is recommended in this research that emotional experiences of disabled people apart from their environment should be given more attention. Another interesting area of future research includes subjective experiences based on the type of disability, analysing the weather experiences differ from congenital or acquired disability.

The limitation of this study consists of the methodology, as a systematic review follows different protocols. Furthermore, some articles which could have contributed to the findings of this research, were not retrievable for appraisal. Yet another limitation of this study is generalisability of findings, as these findings are limited to a South African context.

In conclusion, it is hoped that this review has demystified socio-emotional experiences that disabled people face regarding their disability and has highlighted available areas that have been explored as well as areas that are still in need of further exploration.

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Appendices

Appendix A

Record keeping log

Database searched	Pubmed
Person searching	Rofhiwa Netshifhire
No. of records obtained	505 After timeline limitations (2000-2020): 439
Search string	(socio-emotional or feelings) OR ('inner experiences' or attitudes or 'psychological experiences')) AND (disability or disabled or disabilities or impaired or impairment)) AND 'South Africa'

Database searched	Sabinet
Person searching	Rofhiwa Netshifhire
No. of records obtained	6589 after limit by date is 4890. Filter by title to 75
Search string	socio-emotional OR feelings OR 'inner experiences' OR 'psychological experiences' AND disability OR disabled AND 'South Africa'

Database searched	APA PsychInfo
Person searching	Rofhiwa Netshifhire
No. of records obtained	86, after timeframe limit= 80
Search string	socio-emotional OR feelings OR 'inner experiences' OR attitudes OR 'psychological experiences' OR 'psychological theories' (Su Subjects) AND disability OR disabled OR disabilities OR impaired OR impairment (Su Subjects) AND 'South Africa' (no field selected) NOT caregivers OR family members OR teachers (no field selected).

Database searched	Ebscohost (CINAHL, MEDLINE, Medline Complete, Psychology and Behavioral Sciences Collection
Person searching	Rofhiwa Netshifhire
No. of records obtained	320, limit to date to: 298
Search string	socio-emotional OR feelings OR 'inner experiences' OR attitudes OR 'psychological experiences' (Su Subjects) AND disability OR disabled OR disabilities OR impaired OR impairment (Su subjects) AND 'South Africa' (no field selected)

	NOT caregivers OR family members OR teachers (no field selected).

Database searched	**Tylor & Francis online**
Person searching	Rofhiwa Netshifhire
No. of records obtained	Results : 1,461 Limit to date: 1, 046
Search string	'psychic experiences' AND disability AND 'south africa'

Appendix B

Ten subcategory questions of the CASP for qualitative studies appraisal.

The ten questions were retrieved from Critical Appraisal Skills Programme (2017).

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Appendix C

Adapted CASP for quantitative studies (from Laher & Hassem, 2020).

1. Was there a clear statement of the aims of the research? □Yes □Can't tell □No

Consider: What was the goal of the research? Why it was thought important? Its relevance?

2. Is a quantitative methodology appropriate? □Yes □Can't tell □No

Consider: If the research seeks to examine a relationship between variables or comparison of groups, is quantitative research the right methodology for addressing the research goal?

2.1 Were all the participants accounted for in the results and the conclusion? □Yes □Can't tell □No

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research? □Yes □Can't tell □No

Consider: If the researcher/s has justified the research design (e.g., have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research? (Assess selection bias) □Yes □Can't tell □No

Consider: If the researcher has explained how the participants were selected? Are the individuals selected to participate in this study likely to be representative of the target population? If there are any discussions around recruitment (e.g., why some people chose not to take part)?

5. Was the data collected in a way that addressed the research issue? □Yes □Can't tell □No

Consider: If the setting for data collection was justified? If it is clear how data was collected? If the researcher has justified the methods chosen? If the researcher has made the methods explicit? Were data collection tools shown to be valid? Were data collection tools shown to be reliable? If methods were modified during the study? If so, has the researcher explained how and why?

7. Have ethical issues been taken into consideration? □Yes □Can't tell □No

Consider: If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained? If the researcher has discussed issues raised by the study (e.g., issues around informed consent, anonymity, and confidentiality, or how they have handled the effects of the study on the participants during and after the study)? If approval has been sought from a relevant ethics committee?

8. Was an adequate statistical technique used to analyse the data? □Yes □Can't tell □No

Consider: Was descriptive data provided? Was the sample size large enough for the statistical technique carried out? Was basic assumptions of the statistical test utilised met? Were both significant and insignificant results reported? Did the statistical technique used effectively answer the research question?

9. Was the data analysis sufficiently rigorous? □Yes □Can't tell □No

Consider: If there is an in-depth description of the analysis process? Were the statistical methods appropriate for the study design? If sufficient data are presented to support the findings? To what extent contradictory data are taken into account? Were potential sources of bias discussed?

10. Were psychometric properties discussed? □Yes □Can't tell □No

Consider: Were reliability and validity of the instruments used discussed or analysed?

11. Is there a clear statement of findings? □Yes □Can't tell □No

Consider: If the findings are explicit? If there is adequate discussion of the evidence both for and against the researchers' arguments? If the findings are discussed in relation to the original research question?

12. How valuable is the research?

Consider: If the researcher discusses the contribution the study makes to existing knowledge or understanding? For example, do they consider the findings in relation to current practice or policy? Or relevant research-based literature? If they identify new areas where research is necessary? If the researchers have discussed whether, or how, the findings can be transferred to other populations or considered other ways the research may be used?

Appendix D

Adapted CASP for theoretical papers (from Laher & Hassem, 2020).

1. Was it a theoretical paper? □Yes □Can't tell □No

2. Was there a clear statement of aims for the paper? □Yes □Can't tell □No

Consider: What was the goal of the research? Why it was thought important? Its relevance?

3. Did the paper appropriately address the research aims? □Yes □Can't tell □No

Consider: If there is adequate discussion of the evidence both for and against the researchers' arguments?

4. Was appropriate literature cited or drawn on to answer the research aims? □Yes □Can't tell □No

Consider: Were influential theories or institutions mentioned?

5. Were experts in the field consulted or internationally recognised bodies cited? □Yes □Can't tell □No

6. Is there a clear statement of findings? □Yes □Can't tell □No

Appendix E

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/21/06W**
PROJECT TITLE:	A systematic literature review on socio-emotional experiences of those living with a disability in South Africa.
INVESTIGATOR	Netshifhire Rofhiwa (461128)
SCHOOL/DEPARTMENT OF INVESTIGATOR	SHCD/Psychology
DATE CONSIDERED	11 June 2021
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	No Risk
EXPIRY DATE	31 December 2023

ISSUE DATE OF CERTIFICATE 21 June 2021 **CHAIRPERSON** GEage

(Prof. Gillian Eagle)

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

Signature **Date** 01/07/2021

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Figure 2

Summary of results from included studies

Authors	**Title**	**Study Design**	**Sample** Size	Age range	Sample Gender	**Critical appraisal score**
Van der Heijden et al., (2019)	Additional Layers of Violence: The Intersections of Gender and Disability in the Violence Experiences of Women With Physical Disabilities in South Africa.	Qualitative	30	19 to 54	Female (100%)	8/10
Mavuso & Maharaj, (2017)	Reproductive health barriers facing men and women with disabilities in	Qualitative	16	29 to 40 +	Male: 6 Female: 10	8/10

	Durban, South Africa.					
Naidoo & Ennion, (2019)	Barriers and facilitators to utilisation of rehabilitation services amongst persons with lower-limb amputations in a rural community in South Africa	Qualitative	11	23 to 80	Male: 3 Female: 8	7/10
Muthukrishna et al., (2009)	Gender and Disability: an intersectional analysis of experiences of ten disabled women in Kwazulu-Natal	Qualitative	9	22 to 35	Females	6/10
McKinney & Amosun, (2020)	Impact of lived experiences of people with disabilities in	Qualitative	4	38 to 50	Males: 3 Female: 1	10/10

	the built environment in South Africa					
Swartz et al., (2020)	They don't understand that we also exist": South African participants in competitive disability sport and the politics of identity	Qualitative	22	38 to 50	Male: 16 Female: 6	9/10
Bantjes et al., (2019)	Troubling stereotypes: South African elite disability athletes and the paradox of (self-)representation	Qualitative	22	18 to 67	Male: 17 Female: 5	8/10
Roux & Burnett, (2011)	The extent to which students with disabilities	Qualitative	4	21 to 27	Male: 3	8/10

	are included in elite sport at higher education institutions				Female: 1	
Laas (2012)	Journey through the Trials and Triumphs of Disability	Qualitative	1	18+	Female	9/10
Swartz & Greyling, 2011	Participation in higher education: experiences of students with disabilities	Qualitative	10	18+	Male: 2 Female: 8	8/10
Brooke-Summer et al., (2014)	Perceptions of psychosocial disability amongst psychiatric service users and caregivers in South Africa	Qualitative	18	18+	Not mentioned	8/10

DE Klerk & Ampousah, (2003)	The physically disabled woman's experience of self	Qualitative	40	21 to 60	Females	8/10
Thurston et al.,20200	Sex, support and society: a journey to reclaiming sexuality for individuals living with paraplegia in Cape Town, South Africa	Qualitative	10	18 to 48	Male: 8 Females: 2	9/10
Watermeyer (2009)	Claiming loss in disability	Theoretical	n/a	n/a	none	6/6
Lourens (2018)	Driving in unheard silence and the politics of shutting up.	Theoretical	Mother-infant dyads (n=674)	18+	n/a	5/6
Mutanga (2013)	I am a university student, not a disabled	Theoretical	1	18+	Female	4/6

	student": Conceptualising Identity and social Justice In south African higher education through the Capabilities approach lens					
Watermeyer et al., (2019)	Navigating the Relational Psychic Economy of Disability: The Case of M	Theoretical	n/a	18+	n/a	6/6
Trani et al., (2020)	. Stigma of persons with disabilities in South Africa: Uncovering pathways from discrimination to depression and low self-esteem	Quantitative	196	18 to 89	Males: 76 Females: 120	12/12

Neille (2015)	Beyond physical access: a qualitative analysis into the	Qualitative	30	19 to 83	Male: 15 Female: 15	10/10