An investigation of stress experienced by caregivers of children with intellectual disability in a Western Cape Province population.

Dissertation in partial fulfilment of the requirements for Master of Philosophy in Intellectual Disability Mental Health.

By

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Abstract

Background: Intellectual disability (ID) is described as a neurodevelopmental disorder which occurs during the developmental period and impacts intellectual as well as adaptive functioning across social, cognitive and practical domains. Approximately 3 percent of the South African population has mild to severe forms of ID. It is well described that caregivers of children with ID and other developmental disorders have higher levels of stress related to caring for their child than parents with typically developing children. However, little research has been reported in the South African context.

Objectives: 1. To determine the nature and extent of self-reported symptoms of stress in caregivers of children with intellectual disabilities. 2. To establish which demographic variables and child factors are associated with carer stress. 3. To compare the nature and extent of self-reported stress and demographic and child variables associated with stress in carers of children with intellectual disability with the same measures reported by carers whose children are developing typically.

*Methods***:** This was a purposive, descriptive analytical study. Participants were 59 caregivers whose children attended Red Cross War Memorial Children's Hospital outpatient clinics. The ID group comprised 35 caregivers of children with ID. The control Non-ID group had 24 caregivers of typically developing children. The children's ages ranged from 2 to 10 years. Caregivers were administered a set of four questionnaires: a demographic questionnaire; the Parent Stress Index; the Hospital Anxiety and Depression Scale and the Aberrant Behaviour Checklist that rated the children's behaviour. The data were analysed using IBM SPSS.

Results: Both the ID and Non-ID groups showed elevated scores for self-reported anxiety. The ID group of caregivers reported significantly more problem behaviours in their children than the caregivers in the Non-ID group. Hyperactive behaviour predicted for depression in the caregiver ID group which also reported higher levels of stress and significantly higher levels of depression than the Non-ID group. 49 percent of the ID group caregivers reported levels of depression in the clinical range. Further, the ID group reported significantly more financial difficulties and also more appointments for their child at health facilities than the control group.

Conclusion: Carers in this study setting experienced similar stresses and described similar child behavioural problems as those reported internationally. A significant finding was the high rate of caregivers of children with ID whose depression scores were in the clinical range. Child behaviour was a significant factor associated with caregiver stress and anxiety in both study groups and with depression in caregivers of children with ID. The study findings have implications for the mental health and behavioural support needs of both caregivers of typically developing children and caregivers of children with ID and for a range of services that provide this support.

Declaration

I, *Sarah-Jessica Strachan*, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abbreviations

ABC	Aberrant Behaviour Checklist
DSM	Diagnostic and Statistical Manual of Mental Disorders
HADS	Hospital Anxiety and Depression Scale
HADS A	Hospital Anxiety and Depression Scale—Anxiety
HADS D	Hospital Anxiety and Depression Scale—Depression
ID	Intellectual Disability
NDC	Neurodevelopmental Clinic
PSI	Parent Stress Index
PSIPD	Parent Stress Index—Parent Distress
PSIPCD	Parent Stress Index—Parent-Child Dysfunction
PSIDC	Parent Stress Index—Difficult Child
RCCWMH	Red Cross Children’s War Memorial Hospital
SASSA	South African Social Security Agency

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Chapter one

Introduction and Literature review

1. Introduction

Intellectual disability (ID) is described as a neurodevelopmental disorder which occurs during the developmental period and impacts intellectual as well as adaptive functioning across social, cognitive and practical domains (American Psychiatric Association: DSM-5; Crnic et al., 2017). Worldwide, it is estimated that approximately 1 percent of the population has an intellectual disability with middle to low income countries having an increased prevalence of 2 percent of the population. The prevalence of ID in South Africa has been difficult to establish due to various factors which influence the analysis of this population such as differences in the definition of ID and methods used to measure ID (Adnams, 2016). According to the census conducted by Statistics South Africa (2005), about 5 percent of the South African population has some form of disability and 3 percent of this population have mild to severe forms of ID (Sandy, Kgole & Mavundla, 2013).

Parents or primary caregivers of young and adult children with ID face a unique set of social, psychological and financial challenges resulting in a burden of stress placed on the family (Bhatia et al., 2015). Multiple stressors associated with providing care for their child may result in negative experiences for caregivers that include families feeling taxed and strained familial relationships (Peer & Hillman, 2014). Similar findings have been described in the South African context. Sandy et al. (2013) reported that caregivers living in Limpopo, South Africa, experienced daily struggles with regards to caring for their child with ID. Challenges such as balancing daily chores and caring for their child as well as addressing their child’s behavioural difficulties, surfaced in the interviews conducted by the researchers. The financial impact of caring for a child with ID was a significant burden for the caregivers studied as they felt that the cash grants provided to them by the South African Government were not sufficient to cover the medical expenses of their children (Sandy et al., 2013).

2. Literature Review

The literature review was conducted using the search engines Ebscohost, Google Scholar, South African official websites and other reports and documents and Non-profit Organisation's websites, reports and other documents. The key terms searched were: "stress", "caregivers", "global developmental delay", "parents", "intellectual disability", "resilience", "South Africa", "low-middle income countries". The articles used in this literature review focused on publication dates between 2011-2018. Resources published prior to 2011 were included only if especially pertinent. Out of numerous articles which surfaced during the search; approximately 29 articles were of relevance to this particular study.

This literature review will first describe stress in caregivers of children with intellectual and developmental disabilities from the international literature and then focus on the literature available within the South African context. Although the search terms include "resilience", the focus is on stress.

It is well described in the international literature that caregivers of children with ID and other developmental disorders have higher levels of stress related to caring for their child than parents with typically developing children (Dykens, 2015; Firth & Dryer, 2013; Rajan & John, 2016; Robinson & Neece, 2015; Tervo, 2012). In a study by Neece, Green & Baker (2012), the authors discuss the stress process which comprises four components. These are the external/causal event, cognitive appraisal of the event, coping mechanisms to deal with the event and consequential effects or stress reactions. When caregivers experience the various challenges associated with raising a child with ID, the stress process is triggered, thereby resulting in stress reactions, the manifestations of which may include depression and anxiety (Neece et al., 2012). The presence of symptoms of depression and anxiety have been used in various studies to measure caregiver stress (Bhatia et al., 2015; Firth & Dryer, 2013; Lanfranchi & Vianello, 2012; Leone, Dorstyn & Ward, 2016). Other studies have examined coping styles and physical health as determinants and manifestations of stress (Dykens, 2015). An additional measure used to assess stress included parental distress in relation to feeling that they are not coping with the challenges that arise when raising children with ID (Leone et al., 2016). Studies have also included the components of attachment, spousal relationships, isolation and competence when measuring stress (Miodrag et al., 2015).

Due to there being complex, multidimensional components of stress, various definitions and interpretations of what is meant by caregiver stress have been presented in the literature. This has rendered comparison between different study outcomes, difficult. This study will use the definition of stress as set out by the American Psychological Association, which defines stress as “an uncomfortable emotional experience accompanied by predictable biochemical, physiological and behavioural changes” (APA, 2017). The changes brought about by stress as described in this definition are explained below.

Impact of Stress on Caregivers

The impact that stress may have on caregivers is significant in that it affects various life domains such as mental health, physical health and parenting abilities. The burden of stress due to increased financial burden of care, increased parenting responsibilities and stigma related to developmental disabilities all result in a high risk of psychiatric illness such as depression (Bhatia et al., 2015). Caregivers may deal with emotions such as sadness, anxiety, frustration and even anger in relation to the responsibilities that come with caring for a child with ID. Caregivers may feel a sense of loss and hopelessness as they are “forced” into a particular lifestyle that they have not necessarily chosen for themselves. This lifestyle may feel restricted and socially isolating especially if the community is one in which disability is not accepted (Shahrier, Islam & Debroy, 2016). Systematic reviews as well as population-based studies have confirmed that mothers of children with disabilities, who are usually the primary caregivers, are more likely to present with clinically significant levels of depression, anxiety and stress as compared to mothers with non-disabled children (McConnell, Savage & Breitkreuz, 2014). The stress of caring for a child with extra needs can impact the caregivers' other relationships beyond that with their child and some studies have found that the quality of marital relationships is lower in parents who have children with ID (Norlin & Broberg, 2013).

Caregivers may not only present with mental symptoms or illness, but also physical or somatic ailments. Chronic stress is known to be associated with an increase in problems of physical health. Due to increased caregiving needs of children with ID, parents may not have sufficient time or resources to take care of their own health needs. Ailments described include cardiovascular, immune, gastrointestinal and neurological problems (Miodrag et al., 2015). The interaction of mental health problems and physical ailments as a result of chronic stress, may in turn impact the way in which the caregiver parents the child. Caregiver burnout, negative parent-child relationships and poor parenting skills are all factors which influence the quality of care for children with ID. Caregivers who have positive relationships with their children tend to guide them and give them positive attention, thereby teaching them and developing their skills. In addition, a parent's positive affect has been shown to be associated with the creation of a supportive learning environment and positive outcomes in children's cognitive development (Fenning & Baker, 2012). Stress is complex and may co-occur with features of resilience and positivity, both a focus of recent studies (Jess et al., 2018). Maternal positivity was shown to serve as an independent predictor of stress of mothers whose children had developmental disabilities, and moderated the impact of child behaviour problems on their parenting stress (Jess et al., 2018). Poor parental responses and tenuous relationships between caregiver and child can impact that child's ability to reach their full developmental potential negatively, thereby creating more stress for the caregiver as the child struggles to become independent (Peer & Hillman, 2012).

In summary, stress in caregivers can impact on emotional and physical well-being in addition to the effectiveness of the caregiver's parenting abilities. Notable factors which are associated with stress in caregivers are discussed below.

Factors Associated with Caregiver Stress

1.) Challenging behaviour of the child

Factors which have been found to be associated with caregiver stress include challenging behaviour, social support, access to services, financial circumstances and the level of disability of the child. Caregivers and those working with individuals with intellectual disability often struggle the most with challenging behaviour. The correct terminology which uses the person first approach is ‘behaviours that challenge’. However, it is regularly referred to in the international literature as challenging behaviour and therefore will also be used in this literature review. The term challenging behaviour refers to behaviour that is deemed to be dangerous, distressing or socially inappropriate and is of such intensity or frequency that it leads to physical danger of others or the individual themselves and interferes with quality of life (Thakker, Bamidele, Ali & Hassiotis, 2012). Challenging behaviour can be seen as a form of communication in that it may be used consciously or unconsciously to communicate an individual's needs or emotions. Many studies have found that there is a co-occurrence of challenging behaviour, mental illness and intellectual disability (Thakker et al., 2012).

There are different types of challenging behaviour which can be self-directed, outwardly directed and environmentally directed (Thakker et al., 2012). Due to the increased risk of children with ID presenting with challenging behaviour, the likelihood of parents experiencing stress themselves when managing the behaviour is higher than parents of typically developing children. Stress may increase over time; as the child gets older their behaviour may become less socially acceptable and more difficult to manage. The caregiver may react negatively towards the child when he or she displays challenging behaviour, which in turn reduces the frequency of positive parent-child interactions (Ellingson, Baker, Blacher & Crnic, 2014). Challenging behaviour is a significant influential factor on caregiver stress and many studies have found that the child's emotional and behavioural issues impact parental stress more significantly than the degree of the child's disability (McConnell et al., 2014; Tervo, 2012). The relationship between child behaviour and parental well-being has been described as bidirectional by some researchers as they highlight how challenging behaviour impacts caregiver stress, which may lead to negative parenting styles, which in turn may lead to increased challenging behaviour from the child (McConnell et al., 2014).

2.) Levels of social support

The presence of social support is known to reduce stress and improve well-being in caregivers. However, due to stigma, challenging behaviour and the relational issues that come with raising a child with ID many caregivers do not have the social support that they need. Negative social responses from community members, due to misconceptions about disability, further isolate families and may cause emotional distress (McConnell et al., 2014). The quality of the marital or partner relationship may also be compromised due to the challenges that come with raising a child with ID. Partner support may therefore not be as secure which means that the stress is taken on by one caregiver instead of being shared between two (Norlin & Broberg, 2013). Further, a positive source of support for caregivers may be that of religious practices and affiliations whereby belief in a higher power can be a source of comfort and give meaning to having a child with a disability. The community which is formed through in-common religious practices may be able to offer social support to caregivers as well as practical respite, material support and hands-on caring from fellow members (Leone et al., 2016).

3.) Access to formal resources

Attempting to access resources and services can be challenging due to difficulties which may arise in relation to the kind of services offered as well as transportation costs and logistics. Children with ID require specialised services in order to address their developmental and medical needs. Many studies report that access to support services is difficult and that the extent of specialised services is poor (Bhatia et al., 2015; Cramm & Nieboer, 2011; McConnell et al., 2014). Resources in the form of caregiver knowledge and education are key in impacting on the nature of care and parenting the child with ID receives. Maternal education can empower the caregiver through increased knowledge which improves self-efficacy, making the caregiver feel that they are more capable of handling the challenges that come with raising a child with ID (Ellingson et al., 2014).

4.) Financial difficulties

Caregivers who have a child with a disability generally experience a negative impact on their financial resources due to such reasons as increased health expenses, restricted capacity for employment in the open labour market and the loss of career development opportunities and flexibility (Bhatia et al., 2015; Cramm & Nieboer, 2011; Dykens et al., 2015). Due to the increased health care needs of children with ID, frequent trips to relevant health facilities need to be made which are expensive in terms of transport and facility costs. This is especially true in the early years when initial assessments are being carried out and diagnoses made. Generally, there is a focus on early intervention and children who have been diagnosed with ID are likely to receive referrals to various health therapies. These include physiotherapy, occupational therapy and speech and language therapy, where available, thereby adding to the number of hospital or clinic appointments. Many caregivers are unable to enter into open employment outside the home due to the demands of caring for their child with ID whilst others remain in lower career positions as they do not have the capacity to deal with increased work-related responsibilities (Cramm & Nieboer, 2011).

5.) Level of the child's disability

The level of the child's disability as well as the presence of a comorbid condition may impact the nature and extent of stress the caregivers face. The most commonly reported psychiatric comorbidities found in individuals with ID are anxiety disorders, attention-deficit/hyperactivity disorder and mood disorders (Harris, 2010). In addition, challenging behaviours are commonly described. Caregivers need to manage both the needs that come with having a child with ID as well as those of the second diagnosis and what that condition entails.

In the study by Tervo (2012), it was reported that deficits in social and fine motor skills in the child with developmental delay was associated with increased levels of parental stress. This is partially due to toddlers or young children with these delays showing low levels of autonomy and contributing less to group situations making social interactions taxing and difficult (Tervo, 2012). If the child has mild ID they are generally able to communicate well, learn basic skills for employment and should become relatively independent over time. If the child has moderate to severe ID they may require more hands on care and supervision from the caregiver (Adnams, 2016). Individuals with severe ID may have a small verbal vocabulary and will most likely need continuous support around communication at school and within the home. Children with profound ID require considerable support in carrying out activities of daily living and have significantly reduced language ability. As a result of the difficulties in communication, the expression of emotions and needs may be poorly understood by caregivers. It is also more likely that they will need long-term high support care (Adnams, 2016).

Specific diagnoses in the child with an ID may also impact the level of stress experienced by caregivers as is the case with autism spectrum disorder where parents report higher levels of stress than parents of children with other developmental disorders. This is due to the additional challenges faced by parents of children with autism spectrum disorder in relation to the wide range of behavioural and sensory issues associated with the condition (Firth & Dryer, 2013). Children with a physical disability in addition to ID will need extra attention from caregivers and may face challenges with mobility within the home and broader community. The presence of an additional medical condition may affect the child's medical needs as well as behaviour depending on the nature and extent of co-morbidity (Lanfranchi & Vianello, 2012; Peer & Hillman, 2012; Sarimski, Hintermair & Lang, 2013).

International studies have used various tools and methods to measure and gain an understanding of the level of stress and factors associated with stress. Tools used include the Depression Anxiety Stress Scale (Bhatia et al., 2015), the Hospital Anxiety and Depression Scale (HADS) (Cramm & Nieboer, 2011), Parenting Stress Index (Cramm & Nieboer, 2011; Sarimski et al., 2013), Perceived Stress Questionnaire (Shahrier et al., 2016) and NIMH Disability Impact Scale (Rajan & John, 2016). Methods included both quantitative and qualitative studies which used the above-mentioned scales as well as structured and semi-structured interviews.

Stress in Caregivers of children with ID: The South African Context

When conducting the literature review for this current study; little published or online access research could be found on caregivers and stress in South Africa. Four studies were found which were relevant; two examined caregivers with children with ID and the other two focused on caregivers of adults (dependants/children) with ID. Sandy et al. (2013) used semi-structured interviews to gain an understanding of what the caregivers support needs are and Sadiki & Mashegoane (2019) used in-depth interviews to ascertain caregivers' experiences of caring for their child with ID. Mckenzie & McConkey (2016) used a semi-structured interview to gain information about challenges that caregivers face and their needs in terms of relevant support. In the fourth study, Coetzee (2016) examined a case series of caregivers of adults with ID and aggressive behaviour. The study reported elevated levels of stress in all the parents as well as other mental health problems, including depression. In all studies the researchers highlight that most studies conducted on caring for children with ID have been done in high income countries and there is little literature available on caregivers living in South Africa which is categorised as a low and middle income country by the World Bank. (McKenzie & McConkey, 2016; Sandy et al., 2013).

Impact of stress on Caregivers in the South African context

Sandy et al. (2013) established that compared to international studies, caregivers of children with ID living in South Africa faced many similar challenges which caused stress. In this study, mothers reported that they experience emotions such as anger, frustration and helplessness in relation to the stresses of caring for a child with ID. Some may become distant and withdrawn from their child where challenging behaviour is present as the parent may not know how to cope with the behaviour. This impacts the parent-child relationship and may result in poor care for the child. For many caregivers the lack of respite in seeing to their child's needs caused chronic stress which research shows can lead to burnout (Sandy et al., 2013). The chronic stress which is present as a result of on-going care may also lead to parents becoming frustrated and even aggressive towards their child with ID. Parents in the study by McKenzie & McConkey (2016) admitted that they have at times become physically violent towards their children due to high stress and anxiety.

Factors Associated with Caregiver Stress in the South African context

1.) Challenging behaviour

For the caregivers interviewed in the study by Sandy et al. (2013), stress and anxiety were often brought on by outbursts of challenging behaviour from the children that they were caring for. As a result of challenging behaviour, some children may be labelled as aggressive which in turn can result in social exclusion. This discrimination adds to the stress which caregivers experience as they often do not receive the social support that they need. In addition, they may be restricted in terms of the places they can visit with their children (McKenzie & McConkey, 2016; Sandy et al., 2013).

2.) Levels of social support

In the African context, some traditional beliefs about disability may be negative in nature and are often linked to supernatural intervention. These beliefs impact how disability is dealt with in communities as having a disability may be seen as divine retribution or witchcraft. Some caregivers feel the need to hide their family members with ID due to the stigma and shame attached to these traditional beliefs which in turn results in a lack of exposure of persons with ID in the broader community. Caregivers may not receive the support that they need from other family members and the broader community which can result in higher levels of stress (McKenzie, McConkey & Adnams, 2013; Coetzee, 2016). In addition to stigma, some parents fear that their children will be abused within their communities and so further isolate their children in an attempt to protect them (McKenzie & McConkey, 2016).

Other caregivers are concerned about the burden their child with special needs will place on friends and family and so refrain from visiting and socialising with others resulting in personal isolation (Sadiki & Mashegoane, 2019). Sadiki & Mashegoane (2019) found that even the process of disclosing their child's diagnosis to the extended family was stressful for some caregivers as family members had a negative reaction causing tension and conflict within the family unit. However, other caregivers in the same study found comfort and support from their family members which seemed to reduce the stress experienced by the caregivers.

3.) Access to service and other resources

Caregivers of children with ID in the study by Sandy et al. (2013) felt frustrated by the lack of involvement in the treatment and decision-making processes by health care professionals regarding the care of their child. The inadequate engagement by health care professionals resulted in the caregivers feeling uninformed about their child's diagnosis and future treatment (Sandy et al., 2013). Similarly, Sadiki & Mashegoane (2019) found that caregivers reported that they did not receive adequate information about intellectual disability and felt that they were not equipped to handle their child's special needs. Those caregivers learnt about how to care for their child through interacting with the child themselves thereby developing necessary skills and understanding of the child's disability. Similarly, Sandy et al. (2013) found that even when the parents were informed of their child's diagnosis, the lack of information and understanding regarding the specifics of their child's diagnosis emerged as a stressor. Caregivers reported that they had limited knowledge about the nature of intellectual disabilities or how they can help their child to progress. Caregivers felt that if they had access to services such as support and information they would be better equipped to deal with the challenges that they face as carers.

In South Africa, the provision of services is often implemented through Non-Governmental Organisations due to the lack of resources within the governmental sector. Services are scarce in many of the rural areas and townships which are situated closer to bigger cities (Adnams, 2010; McKenzie & McConkey, 2016). Transport to and from these services is frequently problematic due to poor infrastructure and there are also practical barriers to travelling, such as presence of physical disabilities requiring specialised transport. Transport can also be financially costly which may result in caregivers not attending service appointments with their children. McKenzie & McConkey (2016) found in their study that caregivers may experience stressful situations when their child is sick and in need of medical attention but they cannot use public transport at night due to safety reasons.

4.) Financial difficulties

The South African Government provides financial assistance to caregivers of children with disabilities in the form of a cash Care Dependency Grant. Many caregivers however still struggle financially due to various reasons such as having to pay for medical expenses and specialised equipment (Sandy et al., 2013; Sadiki & Mashegoane, 2019). There are many carers who are not able to work as they have to take care of their child with ID - often the child is not cared for in a facility but by the family (McKenzie & McConkey, 2016). Some caregivers found it difficult to make arrangements for the care of their child and as a result had to leave their employment (Sadiki & Mashegoane, 2019). Financial difficulties therefore add to the burden of stress experienced by the caregivers as they have to worry about needs such as clothing for their children on top of their everyday caring responsibilities (Sandy et al., 2013). A further financial difficulty may arise due to the fact that only children assessed as having severe disabilities are eligible for Care Dependency Grants. Children with less severe levels of disability but high care demands may not receive this form of social assistance.

5.) Level of the child's disability

The burden of care for children with ID is increased should the child have a dual-diagnosis such as an additional physical disability. Some caregivers described in the study by McKenzie & McConkey (2016) reported that they had to spend more time and energy when the individual could not do things for themselves. Physical heavy lifting of those who could not bath themselves or move from one place to the other independently was highlighted by one of the carers in the study.

In summary, against the background of strong international evidence for stress in caregivers of children with ID, there is a lack of published, evidence-based literature describing stress in caregivers of children with ID in South Africa. As a low and middle income country, the prevalence of ID is higher in South Africa than in high income countries (Maulik et al., 2011). There is inequality of access to resources and those with disabilities are marginalised.

Further, individuals with disability and their family members are likely to experience social exclusion as a result of stigma. In addition, families living in disadvantaged areas with children with a disability have the compounded burden of financial difficulties. Caregivers may struggle with challenging behaviour and find it difficult to access the resources that they need in order to care for their child with ID. There are thus many factors which combine to create increased risk for parenting stress (McKenzie & McConkey, 2016).

3. Rationale

Most studies on stress of caregivers of children with ID have been conducted in high income settings. Studies have established that caregivers of children with ID experience more stress than caregivers of typically developing children. The literature describes factors associated with carer stress, including challenging behaviour in the child, lack of social support, inadequate access to resources and financial difficulties. The paucity of literature available on caregivers of children with ID in South Africa and the lack of information about factors that influence the development of stress, results in a gap in evidence upon which to base appropriate and effective interventions. This study aims to gain further understanding of stress reported by caregivers of children with ID in the South African context. Any study in the topic area in the South African setting needs to take into account that high levels of stress are reported in the general population (Herman et al., 2009). Thus, in order to identify that caregiver reported stress may be associated with, or linked to their child's intellectual disability, the study will also examine carers whose children develop typically and who do not have known intellectual or developmental disability. The typically developing group carers will function as a comparison group in order to identify any group differences in caregiver and child factors that may be associated with stress.

4. Aim and Objectives

The aim of this study was to investigate the experience of stress in caregivers of children with intellectual disability in a Western Cape population.

The objectives of this study were:

- To determine the nature and extent of self-reported symptoms of stress in caregivers of children with intellectual and developmental disabilities.

- To determine which demographic variables and child factors are associated with carer stress.
- To compare the nature and extent of self-reported stress and demographic and child variables associated with stress in carers of children with intellectual disability with the same measures reported by carers whose children are developing typically.

Chapter two

Methods

1. Study Design

This was a purposive, descriptive, analytic study.

2. Study Participants

All study participants were recruited from the Outpatient Department of Red Cross War Memorial Children's Hospital (RCWMCH), a tertiary hospital located in Cape Town and that provides a range of healthcare services for approximately 260 000 children per year (The Children's Hospital Trust, 2008). Children are predominantly referred from the hospital’s surrounding geographic and health service referral catchment area within the Western Cape Province.

2.1 Intellectual disability (ID) Group.

The participants in this group were caregivers who have children with intellectual and developmental disabilities who attend the Neurodevelopmental Clinic (NDC) at Red Cross War Memorial Children's Hospital (RCWMCH). The NDC clinic renders comprehensive, specialised services to children and some adolescents with, or at-risk for developmental disabilities. The NDC sees between 3900 and 4200 children per year (combination of first assessments and follow ups) with the majority of children ranging between the ages of 2 years and 6 years old. In a recent audit of new patients, out of 300 children 46.4% had a global developmental delay and 25.8% had autism spectrum disorder (personal communication, Prof Kirsty Donald). The researcher attended the NDC on scheduled days of the week. The researcher recruited participants by examining the hospital folders of the children booked for that day's clinic to determine who met the inclusion criteria. Caregivers were recruited as potential participants if their child attended at least one NDC clinic and had a diagnosis or assessment of intellectual disability or global developmental delay from that clinic. In the early years, especially in children with mild and moderate global developmental delays, a formal diagnosis of ID may not have yet been made due to their young age. For the purposes of study nomenclature, children with diagnosed ID or global developmental delay were included in the ID group.

2.2 Non- intellectual disability (Non-ID) control group

The participants in this group are caregivers of children who attended the Red Cross Children's Hospital Outpatients Services other than the Neurodevelopmental Clinic and who are developing typically. The caregivers were recruited from those waiting with their child in the reception areas of the Medical Outpatient Clinic (S27) and the Ear Nose and Throat Clinic (ENT). The Non-ID Group participants were identified purposively from those attending the scheduled clinic on that day and were included if they considered that their child's development was typical – namely, within normal limits and without a significant, chronic health condition (for example a congenital cardiac condition).

3. Sampling, inclusion and exclusion criteria

The study participants comprised 59 caregivers, 35 in the ID group and 24 in the Non-ID group. The participants children were between two years and 17 years of age. The two groups were not individually matched in age but were within a similar age range. The participants were either the primary caregiver or the co-caregiver (for example a family member within the child's household). All the participants were sufficiently conversant in English or Afrikaans and were able to give informed consent. Of the potential participants, none were excluded due to difficulties with communication in English.

4. Outcome measures and measurement tools

The primary outcome measured was stress in carers. Information was derived from an interview comprising standardised questionnaires that were administered to the participants in a quiet, private clinic room at the NDC. The questionnaires were administered by the primary researcher who is a qualified social worker with experience in working with caregivers and families with children with intellectual and developmental disabilities. All questionnaires were in English and verbally administered; verbal translation into Afrikaans was not necessary as all participants could communicate in English. The full interviews took between 30-50 minutes to complete and were administered in one single session. Participants were given a small non-monetary gift to thank them for their time.

The following questionnaires were administered to the caregivers:

4.1 Demographic questionnaire

The demographic questionnaire took approximately 10 minutes to complete.

Information was recorded for:

a) Caregivers: Includes age, sex, home language, relationship to child, own relationship status, governmental or other social assistance received, employment status. (see appendix A for questionnaire).

b) Child: Age, sex, home language, description of disability. These are the demographic child factors referred to in the objectives (see appendix A for questionnaire).

4.2 Aberrant Behaviour Checklist (ABC)

The Aberrant Behaviour Checklist is a widely used validated scale to assess behaviour in children and adults with intellectual disability. It was originally developed to assess behavioural response to interventions. The scale has especially been used for children with autism spectrum disorder. It consists of a 58 item questionnaire administered to caregivers and describes 5 behavioural symptom areas, namely, irritability, lethargy, stereotypathy, hyperactivity / noncompliance and inappropriate speech (Aman et al., 1985). The ABC takes approximately 15 minutes to administer. It has been used in a number of published South African studies involving children with intellectual and other developmental disabilities, including vertically transmitted AIDS / HIV (Smith, Adnams & Eley, 2003). The behaviour measures for all of the children refer to the child factors as stated in the study objectives.

4.3 Parenting Stress Index—Short Form (PSI-SF)

The Parenting Stress Index (PSI) is a widely used and well-researched measure of parenting stress and has been adapted into a short version (PSI-SF) containing 36 items in response to researchers and clinicians' need for a shorter tool. The PSI-SF utilises three subscales namely Parenting stress, Parent-Child Dysfunctional Interaction and Difficult Child (Abidin, 1995). The domains assessed in this scale are: Anxiety/Mood, Relationships and Attachment, Parent, Caregiver, Family Mental Health and Functioning. The average time taken to complete the PSI-SF is 10 minutes. The PSI-SF has been tested and found to be both reliable and valid (Abidin, 1995). Researchers examining stress in caregivers of children with ID have used the PSI in their study (Sarimski et al., 2013) and the PSI-SF has been used in South Africa to research stress in caregivers of adults with ID (Coetzee, 2016).

4.4 Hospital Anxiety and Depression Scale (HADS)

The HADS was originally developed by Zigmond and Snaith (1983) and is used to assess the possible and probable causes of anxiety and depression within a clinical or nonclinical setting. The HADS consists of 14 items in two subscales (HADS-A (anxiety) and HADS-D (depression)) of 7 items each. These subscales measure mutually exclusive levels of anxiety and depression (Kaur et al., 2015). The HADS has shown internal consistency and validity for identification and screening of the psychiatric diagnostic symptoms of anxiety and depression (Cramm & Nieboer, 2011). Because of these qualities and brevity and speed of use (approximately 5-10 minutes), and the fact that it may be administered by non-clinicians, the HADS has been used extensively in international research as well as in mental health clinical practice (Stern, 2014). Because the HADS was intended for use with medical patients who often have physical complaints, the items were designed to de-emphasize physical and somatic, symptoms, such as fatigue and instead focus on psychological symptoms. The HADS has been used to examine anxiety and depression related stress in caregivers of children with ID and has also been successfully used within the South African context as a tool for measuring anxiety and depression in clinical research populations (Pappin, Wouters & Booysen, 2012).

Because of the high validity and reliability of the HADS with internationally used psychiatric diagnostic criteria for anxiety and depression (Cramm & Nieboer, 2011), including the Diagnostic and Statistical Manual of Mental Disorders-IV, (American Psychological Association, 2000), the subscale scores may reflect valid levels of anxiety and depression. The responses for 7 items of each of the subscales are measured on a Likert scale from 0 (no problem) to 3 (a problem) with a maximum of 21 for each subscale. A high score indicates greater number of symptoms of either anxiety or depression. Scores of less than 8 indicate few symptoms (non-clinical range); scores of 8-10 reflect mild anxiety or depression; scores of 11-14 indicate moderate symptoms and scores of 15-21 indicate severe symptoms.

5. Statistical Analysis

Demographic and questionnaire data were coded and entered to a data spreadsheet. Data were analysed using IBM Statistical Package for Social Sciences (SPSS) version 25.

Descriptive categorical variables were summarised as frequencies or percentages. Numerical data for both groups were expressed as mean and standard deviations or median and range, according to their distribution. Within and between group means and medians were compared using t tests, Anova and Wilcoxon rank sum tests as appropriate. The p-value was set at a confidence interval of 95% (p-value equal to or less than 0.05). Variable correlations were determined using Pearson Correlations. Stepwise linear logistic regression analysis was performed to ascertain the association of independent variables that may contribute to stress in caregivers in both groups. Reliability tests tell how well test-takers can be differentiated by their scores on a study outcome measure. Reliability of the standardised questionnaires was determined using Guttman's lambda (λ)-2. The lambda 2 co-efficient was developed for assessment of the reliability of multi-item measurement tools (Guttman, 1945). Guttmans' lambda-2 is a co-efficient of internal consistency and is a more robust method for measuring reliability than the commonly used Cronbach's alpha co-efficient.

A power calculation for the study, using effect size 0.05, statistical probability level of 0.05, yielded a sample size of 105. Given that this is an exploratory, descriptive study, the use of power analysis for sample size, may not be valid. However, it is reported here for the purpose of research rigor.

6. Ethical Considerations and Confidentiality

An information sheet was given to the participants outlining the aims of the study, inviting participation and assuring anonymity and confidentiality. Participation was voluntary and was not remunerated. Participants were asked to sign a consent form. The raw data was stored in a locked cupboard so as to adhere to strict confidentiality standards. Participant identities were coded and entered data stored on a password protected computer.

Approval for the study was obtained from the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee. Permission was granted by the Department of Health and RCWMCH to access the relevant clinics for the purposes of recruiting participants for the study.

The primary researcher was a qualified Social Worker who is registered with the South African Council for Social Service Professionals. Due to the nature of the study, some participants reported that they experienced high levels of stress caring for their child. The researcher provided appropriate professional support and, where necessary, clinical and other referrals. The researcher had access to own mental health support and supervision by a clinical psychologist in the field of mental health and intellectual disability. The study complied with the International Declaration of Helsinki.

Chapter three

Results

Parametric and non-parametric data are presented as mean and standard deviation and median and range respectively. Comparisons of group variables are reported according to tests used - Student t-test, Anova or Pearson Chi-Square (χ^2). Reliabilities were reported as Guttner's lambda-2 coefficient.

1. Caregiver Demographic Data

1.1 Study Participants

A total of 59 participants were recruited for this study, 35 in the intellectual disability (ID) group and 24 in the non-intellectual disability comparison (Non-ID) group. Most participants, 91.5% (n=54) were female and 8.5% (n=5) were male. Within the ID group, 94.3% (n=33) were female and 5.7% (n=2) were male. The Non-ID group sex distribution was similar, comprising 87.5% (n=21) females and 12.5% (n=3) males. The median ages of the ID and Non-ID participants were 34 years (range 21-62) and 33 years (range 23-49) respectively. A non-parametric independent-samples median test for age difference showed no difference between ages of caregiver participants in the two groups (p=0.968).

1.2 Caregiver Citizenship, Language and Relation to the child

82.9% (n=29) of ID group participants reported being South African citizens compared to 91.7% (n=22) of the Non-ID group; this difference was not statistically different (χ^2 (1, n=59) p = 0.332).

As is shown in the Table 1, mixed languages (that is, more than one home language) was most commonly reported by all participants. More participants in the ID group spoke mixed languages at home than in the Non-ID group but the difference was not statistically significant. IsiXhosa and Afrikaans were the predominant single home languages. Too few participants spoke both English and Afrikaans at home for meaningful analysis. As per the inclusion criteria, all the participants were able to respond in English.

Table 1: Home language of ID and Non-ID caregivers (n=59)

Home language	ID Group (n=35) n (% of group)	Non-ID Group (n=35) n (% of group)	Total n (% of group)
English	8 (23.5)	3 (12.0)	11 (18.6)
Afrikaans	2 (5.9)	6 (24.0)	8 (13.6)
isiXhosa	2 (5.9)	4 (16.0)	6 (10.1)
Mixed	23 (67.6)	11 (44.0)	34 (57.6)

Table 2 describes the relationship of the caregiver participant to the child attending the hospital clinic. The majority of caregivers in both groups were biological mothers of the children and these rates were similar in both groups.

Table 2: Caregiver's relationship to the child (n=59).

Family Member	ID Group (n=35) n (% of group)	Non-ID Group (n=24) n (% of group)
Biological mother	29 (82.9)	21 (87.5)
Biological father	2 (5.7)	3 (12.5)
Grandparent	2 (5.7)	0
Other family member	1 (2.9)	0
Other	1 (2.9)	0

The participant groups reported relatively similar partnership / marital status. The caregiver partner / marital status is summarised in Table 3.

Table 3: Marital status of the caregivers (n=59).

Caregiver status	ID Group (n=35) n (% of group)	Non-ID Group (n=24) n (% of group)	Total (n=59) n (% of group)
Married	21 (60)	16 (66.7)	37 (62.7)
Single or Divorced	11 (31.4)	5 (20.8)	16 (27.1)
Has partner - lives with caregiver	3 (8.5)	2 (8.3)	5 (8.5)
Has partner – lives separately	0	1 (4.2)	1 (1.7)

1.3 Caregiver Employment, Household number and Number of Dependants

Caregiver employment data are summarised in table 4. There was no difference between the groups' employment status. Over half of the participants (54,3%, n= 19) in the ID group reported that they left their employment at some point due to their child's disability. There was no significant difference between the two groups' employment status.

Table 4: Caregiver Employment status (n=59).

Employment status	**ID Group (n=35) n (% of group)**	**Non-ID Group (n=24) n (% of group)**
Employed (full-time/part-time)	20 (57.2)	13 (54.2)
Unemployed	14 (40)	11 (45.8)
Retired	1 (2.9)	0

The ID group caregivers reported fewer people living in their households than the non-ID group. Of the ID group, 62.9% (n=22) had between 2-4 household members and 37.2% (n=13) had more than 4 household members. In the Non-ID group, 45.8% (n=11) had 2-4 household members and 54.2% (n=13) had more than 4 household members. There was no statistical difference between the groups' household numbers.

68.6% (n=24) of the participants in the ID group had up to two dependants and 31.4% (n=11) had three or more dependants. In comparison, 54.2% (n=13) of the Non-ID group had up to two dependants while 45.9% (n=11) had three or more dependants. The ID caregivers reported to have a lower total number of dependants.

The majority of participants in the Non-ID group (87,5%; n= 21) reached secondary schooling level and 2 participants (8,3%) studied further after completing secondary schooling. In the ID group 57,1% (n=20) of participants attained secondary schooling level however, more ID participants (34,3%; n=12) furthered their studies at a post-secondary level. Although there was no difference in the total years of education between the groups [t (57)=1.26, p=0.173)], the difference in years of post-secondary education was significant [t (57)=5.30, p=0.0.02)].

1.4 Caregiver Financial circumstances, South Africa Social Security Agency (SASSA) grants and number of hospital / clinic appointments

Pearson’s Chi-squared test showed that significantly more participants in the ID group, 82.9% (n=29) reported that they experienced financial difficulties than those in the non-ID group (58.3% (n=14), [χ^2 (1)=4.33,p = 0.037)]. In the ID group, 54% (n=19) received 1 SASSA grant and 20% (n=7), received 2 grants. In the non-ID group, 58.3% (n=14) received 1 grant but none received 2 grants. The IDD caregivers’ households received a mean of 0.94 (SD=0.69) SASSA grants per household compared with 0.63 (SD=0.50) per household in the non-ID group. The difference in number of SASSA grants received was statistically significant [t(2.07), p=0.043)].

68.6% (n=24) of the ID participants attended between 1 and 4 appointments with their child in the six months before the study and 31.5% (n=11) attended 5 or more appointments in the same period. 95.8% (n=23) of the non-ID participants attended up to 4 child appointments in the last six months and only 4.2% (n=1) had attended 5 or more appointments. The children in the ID group did not have significantly more total appointments booked than the non-ID children [t(56)=1.75,(p = 0.085.)].

There was no difference between the groups in travel times to attend clinic appointments [t(56)=0.889, p = 0.378)]. However, the majority of the ID group carers (57.1%; n=20) reported that they experienced difficulty in transport or travelling due to their child’s disability.

2. Child Demographic Data

2.1 Child Age, Level of ID and Education status

There were 35 children in the ID group and 24 in the Non-ID group, matching the number of caregivers in this study. Of the total number of children, 67.8 % (n=40) were male and 32.2 % (n=19) were female. Sex distribution was 68.6 % (n=24) and 66.7 % (n=16) male and 31.4 % (n=11) and 33.3 % (n=8) female in the ID and Non-ID groups respectively.

The median ages for the children were 66 months (range=23 - 49) in the ID group and 69 months (range=33-121) in the Non-ID group. A non-parametric independent-samples median test for age difference showed no difference between ages of children in the two groups (p=0.783).

The children’s level of intellectual disability is summarised in Table 5. Records on the level of intellectual disability were missing from the hospital folders of 6 children in the ID group. Consistent with the study exclusion criteria, no children in the Non-ID group were reported in the medical folder as having intellectual disability.

Table 5: Children’s level of intellectual disability in the ID group as reported in the child’s medical folder (n=35)

Level of ID	Number (percentage)
Borderline	4 (11.4)
Mild	11 (31.4)
Moderate	14 (40)
Missing data	6 (17.1)

Table 6 summarises the participating children’s education status.

Table 6: Child education status by group (n=59)

Education Status	ID group n (% of group)	Non-ID group n (% of group)
Registered early childhood development centre	10 (28.6)	6 (25)
Informal crèche	0	1 (4.2)
Mainstream school	4 (11.4)	14 (58.3)
Mainstream, awaiting placement at a special school	2 (5.7)	0
Special school	11 (31.4)	0
At home due to young age or no education placement	3 (8.6)	3 (12.5)
At home awaiting placement	5 (14.2)	0

59.3 % (n=35) of caregiver participants reported that a community or family member had teased or harmed their child. 71.2 % (n=42) of all participants reported concerns about the safety of their child.

2.2 Aberrant Behaviour Checklist (ABC)

This scale measured caregiver reports of their child's behaviour on 5 sub scales. The scores for the sub scales of Irritability, Lethargy, Stereotypy and Hyperactivity were statistically higher for the ID group than the non-ID group indicating more problem behaviours reported by the caregivers for the children with ID. While the scores for the last sub scale of inappropriate speech were slightly higher in the ID group; these results did not yield a statistically significant difference between the two groups. See table 7 for a summary of the ABC sub scales results.

Table 7: Aberrant Behaviour Checklist (ABC) scores: Caregiver ratings of children's behaviour for the ID and Non-ID groups. (n=59)

Aberrant Behaviour Checklist Subscale	Group Score Mean (standard deviation)		Students t test	
	ID group (n=35)	Non-ID group (n=24)	t value	p value
ABC I (Irritability)	14.77 (11.27)	8.42 (6.77)	2.70	0.009*
ABC II (Lethargy)	7.74 (7.99)	3.92 (5.29)	2.21	0.031*
ABC III (Stereotypy)	3.74 (5.04)	0.21 (0.66)	4.10	0.000*
ABC IV (Hyperactivity)	22.66 (11.44)	10.88 (8.73)	4.26	0.000*
ABC V (Inappropriate Speech)	2.78 (2.52)	1.75 (1.54)	1.77	0.083

**Correlation is significant at the 0.05 level (2-tailed)*

The caregivers in both groups reported that they would like more information on children's behaviour and behaviour management; 74,3% (n=26) in the ID group and 83,3% (n=20) in the Non-ID group. 77,1% (n=27) of caregivers of children with ID stated that they would like more information on intellectual and developmental disabilities.

2.3 Parent Stress Index- Short Form (PSI)

The PSI questionnaire measured 3 areas of caregiver reported stress. The findings are detailed in Table 8. In the Parent Distress and Difficult Child sub scales, the mean scores for each group were not significantly different. The ID group mean score for the parent child dysfunction sub scale was significantly higher than the non-ID group, indicating significantly higher reported levels of stress in this area.

Table 8: Parent Stress Index-Short Form scores for ID and Non-ID caregiver participants (n=59)

Parent Stress Index-Short Form Subscale	Group Score Mean (standard deviation)		Students t test	
	ID group (n=35)	Non-ID group (n=24)	t value	p value
Parental Distress	36.06 (6.87)	33.46 (6.26)	1.48	0.145
Parent-Child Dysfunctional Interaction	32.49 (6.26)	28.92 (6.14)	2.05	0.045*
Difficult Child	33.51 (6.36)	30.92 (6.72)	1.51	0.138

**Correlation is significant at the 0.05 level (2-tailed)*

2.4 Hospital Anxiety and Depression Scale (HADS)

This questionnaire measured self-reported anxiety and depression in caregiver participants. Higher scores indicate worse anxiety or depression. The results are summarised in Table 9. There was no statistical difference between mean scores for each group in the anxiety scale. The mean scores for depression scale were significantly higher in the ID group than the non-ID group, showing that caregivers in the ID group reported significantly higher levels of depression.

Table 9: Hospital Depression and Anxiety Scale (HADS) scores for ID and Non-ID caregiver participants (n=59).

Hospital Depression and Anxiety Scale Subscale and Total scores	Group Score Mean (standard deviation)		Students t test	
	ID group (n=35)	Non-ID group (n=24)	t value	p value
Anxiety HADS A	8.97 (4.92)	7.67 (3.68)	1.10	0.274
Depression HADS D	7.71 (4.25)	5.67 (2.73)	2.25	0.028*
Total HADS Anxiety and Depression (HADS A + HADS D)	16.69 (8.24)	13.33 (5.75)	1.72	0.090

**Correlation is significant at the 0.05 level (2-tailed)*

Table 10 describes the symptoms according to clinical severity levels for the HADS anxiety and depression scales.

Table 10: HADS anxiety (HADS A) and depression (HADS D) symptom levels for the ID and Non-ID caregiver groups

HADS Sub Scales	**Levels of HADS Symptoms**					
	Mild (score 0-7)		**Moderate (score 8-10)**		**Severe (score 11-21)**	
	ID (n=35)	**Non-ID (n=24)**	**ID (n=35)**	**Non-ID (n=24)**	**ID (n=35)**	**Non-ID (n=24)**
Anxiety n (%)	15 (42.9)	12 (50.0)	7 (20.0)	6 (25.0)	13 (37.1)	6 (25.0)
Depression n (%)	18 (51.4)	20 (83.3)	8 (22.9)	3 (12.5)	9 (25.7)	1 (4.2)

2.5 Pearson Correlation Analysis: ABC, PSI and HADS

Pearson correlation analysis was undertaken to identify associations between caregiver stress (PSI), and anxiety and depression (HADS) outcomes as independent measures and child rated behaviour (ABC) as dependent outcomes (see Table 10). The analysis shown in table 11 demonstrated numerous statistically significant correlations between the different dependent measures, indicating that there was confounding, or overlap between these measures. For example, a significant positive correlation was found between the child behaviour (ABC) results and two of the PSI subscales (Parent-Child Dysfunctional Interaction and Difficult Child) that are based on caregiver perceptions of negative child behaviours. In addition, there were significant positive associations between the PSI Parent Distress and HADS anxiety and depression scores, reflecting the overlap in the clinical conditions measured by these scales. There were no significant correlations with caregiver stress, anxiety or depression on any of the child or caregiver demographic variables.

Table 11: Pearson correlations between scores for Aberrant Behaviour Checklist (ABC), Parent Stress Index Short-Form [PSI: Parent Distress (PSIPD), Parent Child Dysfunction (PSIPCD), Difficult Child (PSIDC)] and Hospital Anxiety and Depression Scale anxiety (HADS A) and depression (HADS D) subscales (n=59).

		ABCI TOT	ABCII TOT	ABCIII TOT	ABCIV TOT	ABCV TOT	PSIPD TOT	PSIPCD TOT	PSIDC TOT	HADS A TOT	HADS D TOT
PSIPD score	**Pearson Correlation**	.395**	.215	.314*	.434**	.310*	1	.637**	.616**	.517**	.571**
	P value	.002	.103	.016	.001	.020		.000	.000	.000	.000
	N	59	59	59	59	56	59	59	59	59	59
PSIPCD score	**Pearson Correlation**	.620**	.432**	.347**	.606**	.450**	.637**	1	.775**	.491**	.488**
	P value	.000	.001	.007	.000	.001	.000		.000	.000	.000
	N	59	59	59	59	56	59	59	59	59	59
PSIDC score	**Pearson Correlation**	.691**	.339**	.280*	.673**	.437**	.616**	.775**	1	.574**	.489**
	P value	.000	.009	.032	.000	.001	.000	.000		.000	.000
	N	59	59	59	59	56	59	59	59	59	59
HADS A score	**Pearson Correlation**	.488**	.276*	.268*	.495**	.447**	.517**	.491**	.574**	1	.618**
	P value	.000	.035	.040	.000	.001	.000	.000	.000		.000
	N	59	59	59	59	56	59	59	59	59	59
HADS D score	**Pearson Correlation**	.289*	.220	.183	.403**	.232	.571**	.488**	.489**	.618**	1
	P value	.027	.094	.164	.002	.086	.000	.000	.000	.000	
	N	59	59	59	59	56	59	59	59	59	59

***Correlation is significant at the 0.01 level (2-tailed)*

**Correlation is significant at the 0.05 level (2-tailed)*

2.6 Regression Analysis

In order to ascertain the abilities of the respective child behaviours to predict for caregiver distress, step-wise linear regression analysis was performed. Caregiver anxiety and depression, and one PSI subscale (Parental Distress) that was not based on child behaviour, were the dependent variables and the ABC subscales were the independent variables. Using the SPSS programme, models were set up for three of the caregiver interview outcomes, namely Parent Distress (from the Parent Stress Index Short-Form) and Anxiety and Depression (from the HADS). The participant groups were combined for the analysis of Parent Distress scores and HADS Anxiety as there was no significant difference between the groups for these outcomes. The HADS Depression analysis was performed separately for each group because the group scores were significantly different for this outcome. The regression models involved stepwise entry of the 5 behaviours of Irritability, Lethargy, Stereotypy, Hyperactivity and Inappropriate speech.

2.6.1 Statistical regression—Parent distress (PSIPD) and child behaviour (ABC) outcomes

The model for Parent Distress showed that of the 5 ABC measured behaviours, Hyperactivity predicted significantly for Parent Distress (R square = 0.129, F(1,54 = 7.96) p=0.007). This finding shows that hyperactive behaviour contributed 12.9% of the variance of Parent Distress scores for the combined study caregiver groups. The standardised beta coefficient was +.358 indicating a positive relationship between the behaviour variable and the independent measure.

2.6.2 Statistical regression—Anxiety (HADS A) and child behaviour (ABC) outcomes

A two model stepwise regression analysis was derived for HADS Anxiety as the dependent variable and behaviour as the independent variable. In the first model, Irritability on its own predicted for 30.1% of the variance of all caregivers' anxiety (R square = 0.301, F(1,54=23.21), p=0.000). The standardised beta coefficient was +.548. The second model included two behaviour variables that in combination contributed significantly to caregiver anxiety. The variables were Irritability and Inappropriate speech. The combined prediction, or contribution to, variance of HADS Anxiety scores, was 35.1% (R square = 0.353, F(2,53)=14.43, p=0.000). The difference between the combined contribution and that of Irritability alone was 5%, indicating that in combination, the variables predicted for higher anxiety scores than for Irritability alone. The standardised beta coefficient for the second HADS Anxiety model was +.436 which again indicated a direct positive relationship between the behaviour variable and the caregiver anxiety.

2.6.3 Statistical regression—Depression (HADS D) and child behaviour (ABC) outcomes

The third dependent caregiver variable, HADS depression was similarly analysed using stepwise regression to establish the extent that child behaviours, as independent variables predicted for depression scores. In this model, Hyperactivity predicted significantly for the combined caregiver group depression scores. The contribution of Hyperactivity to variance of all caregiver depression scores was 17.2% (R Square = .172, F(1,54)=11.25, p =.001) and the standardised beta coefficient = +.415. Since there was a significant difference between the scores of the two groups on this variable, separate stepwise regression models were derived for each study group (ID and Non-ID group caregivers). For the ID group, Hyperactivity predicted for 19.6% of variance in the caregivers' depression scores (R square = .196, F(1,30) =7.33, (p=.011)] indicating a slightly higher percentage (19.6%) than the combined group. In the non-ID group model, none of the child behaviours predicted for the dependent (HADS Depression) variable. This finding indicates that the significant contribution of Hyperactivity to depression in the combined caregiver groups was due to the ID group and not the non-ID group. In other words, hyperactivity predicted for depression in caregivers of children with ID but not in caregivers of typically developing children.

2.7 Statistical analysis of questionnaire reliability.

Although validated internationally, there are no reports of the psychological properties of the PSI scales in South African populations. The internal consistency of each standardised questionnaire administered to the study participants was assessed by calculating Guttman's lambda co-efficient (λ-2). The HADS total score as well as the HADS A and HADS D subscales were analysed. The results of the internal consistency analysis are shown in Table 11. The reliability estimates of the measures used in the study ranged from adequate to excellent, indicating a satisfactory to excellent degree to which the participants' responses were consistent across the multiple-item scales.

Table 12: Statistical reliability analysis using Guttman's lambda (λ-2) coefficient for the Aberrant Behaviour Checklist (ABC); Parent Stress Index Short-Form (PSI); Hospital Anxiety and Depression Scale (HADS) subscales administered in the study population. (n=59).

Study measure	Guttman's lambda-2 coefficient	Reliability level
ABC I (Irritability) (n=15 items)	0.937	Excellent
ABC II (Lethargy) (n=16 items)	0.907	Excellent
ABC III (Stereotypy) (n=8 items)	0.913	Excellent
ABC IV (Hyperactivity) (n=16 items)	0.952	Excellent
ABC V (Inappropriate Speech) (n=4 items)	0.706	Adequate
PSI: Parental Distress (n= 12 items)	0.791	Adequate
PSI: Parent-Child Dysfunctional Interaction (n= 12 items)	0.831	Good
PSI: Difficult Child (n= 11 items)	0.827	Good
HADS Total (n=14 items)	0.835	Good
HADS Anxiety (n=7 items)	0.770	Adequate
HADS Depression (n=7 items)	0.700	Adequate

Guttman's lambda-2 coefficient:

1.0 ≥ λ-2 ≤ 0.9 = excellent
0.9 ≥ λ-2 ≤ 0.8 = good
0.8 ≥ λ-2 ≤ 0.7 = adequate
0.7 ≥ λ-2 ≤ 0.6 = below adequate

Chapter four

Discussion and Conclusion

1. Discussion

This study aimed to investigate the stress experienced by caregivers of children with intellectual and developmental disabilities in a Western Cape population. The objectives were to explore the nature and extent of the self-reported stress within, and between the groups as well as to determine the child and demographic factors which are associated with caregiver stress. The findings met the study objectives and were largely supported by literature reports from elsewhere. Findings show that carers in this study setting experience similar stresses and describe similar child behavioural problems as other studies.

As might be expected due to the population group studied namely caregivers of children, and the geographical area served by RCWMCH, there were no notable demographic differences between the two caregiver groups. The ID and Non-ID caregiver groups were similar in age, gender, and marital/partnership status. In both groups, the majority of participants were the biological mothers of the children. There were no differences in the age distribution or sex in the child ID and Non-ID groups showing homogeneity between the groups for these demographic factors.

1.1 Financial difficulties

Although results showed that there was no difference in the employment status of both caregiver groups, a significantly higher percentage of caregivers in the ID group reported experiencing financial difficulties than those in the Non-ID group. Greater financial distress was reported in the ID group despite this group receiving more government social welfare cash grants on average per household than the Non-ID group as well as a lower number of dependants per household. These findings are supported by international research which shows that caregivers of children with a disability generally experience a negative impact on their financial resources due to the personal costs of meeting the care needs of their children over and above those of typically developing children. (Bhatia et al., 2015; Cramm &

Nieboer, 2011; Dykens et al., 2015). A possible contributory factor to the increased financial difficulties in the ID group may be that over 50% of ID group participants reported to have left their employment to care for their child due to their child's disability, thereby experiencing loss of previous income. This finding was corroborated by the South African study by McKenzie & McConkey (2016), which reports that caregivers of children with disabilities were frequently unable to work in the open labour market in order to provide care for their child at home.

The majority of the participants in the ID group stated that they experienced difficulties in transport due to their child's disability. Transport difficulties, including extra costs of specialised transport services needed to access health care facilities have been reported elsewhere as an additional cause of stress to caregivers (McKenzie & McConkey, 2016; Cramm & Nieboer, 2011).

1.2 Children's behaviour (ABC)

Caregivers reports of children's behaviour were measured using the Aberrant Behaviour Checklist (ABC). Results showed that the ABC scores for children with ID were significantly higher, indicating more problematic behaviour than that rated by caregivers in the Non-ID group in 4 of the 5 areas of behaviour examined. The behaviours for which significantly more problems were reported in the ID group were hyperactivity, irritability, lethargy and stereotypy. These findings are consistent with other studies that describe children and adults with ID as being at a greater risk of presenting with challenging behaviours and negative or challenging behaviours being stressful for caregivers (Ellingson et al., 2014). Similarly, in a South African study, Sandy et al. (2013) reported that stress and anxiety was often brought on by outbursts of challenging behaviour from the children that they were caring for. This finding has important implications for understanding stress experienced by caregivers. Other studies report that behavioural and emotional difficulties of children with ID impact parental stress more significantly than the degree of the child's disability (McConnell et al., 2014; Tervo, 2012). The 5th area of behaviour, inappropriate speech, did not yield a significant difference between the two groups.

1.3 Caregiver stress (PSI)

The caregivers in the ID group reported higher levels of stress than the Non-ID group in each domain measured by the Parent Stress Index (PSI). However, only the parent-child dysfunctional interaction outcomes showed a statistically significant difference between the two groups. This sub scale of parent child dysfunction refers directly to the child and how satisfied the caregiver feels with the child and their interactions with that child. This finding is similar to other studies which reported that difficult behaviour in the child with a disability can elicit negative reactions from the caregiver such as emotional withdrawal which reduces the frequency of positive parent-child interactions (Ellingson et al., 2014; Sandy et al., 2013). Whilst the ABC findings showed higher reported behaviour problems in the ID group, the scores for parent distress and difficult child in the PSI were not statistically different. This finding is compared with other studies' reports that caregivers of children with ID experienced a significantly higher level of stress than those with typically developing children (Dykens, 2015; Firth & Dryer, 2013; Rajan & John, 2016; Robinson & Neece, 2015; Tervo, 2012). The parent distress sub scale assesses the caregiver's own feelings regarding their role as a parent and whether they feel competent, conflicted or supported. A possible explanation for the outcome on this domain is that the questions asked identify caregivers' own convictions of being a parent rather than factors relating to the child, and that the overall confidence in parenting per se, was not less in the ID group.

1.4 Caregiver depression (HADS D)

The Hospital Anxiety and Depression Scale is a widely used research tool and although not normed in a South African population, the questionnaire comprises self-reported symptoms of anxiety and depression that are internationally validated in the major screening and diagnostic schedules. In the depression scale, there were significantly higher scores for the ID group than the Non-ID group. Consistent with this finding, other studies have reported that caregivers of children with disability manifest with depression symptoms as a reaction to the stress experienced from caring for their children (Neece et al., 2012). Further, systematic reviews as well as population-based studies have confirmed that mothers of children with disabilities, who are usually the primary caregivers, are more likely to present with clinically significant levels of depression as compared to mothers with non-disabled children (McConnell, Savage & Breitkreuz, 2014). Of note, in this study, a high percentage of caregivers in the ID group scored within the clinical range of self-reported symptoms (between 8-21) on the depression scale. This is of concern and has implications for not only the caregiver's mental health but also the quality of care the child receives. Recent studies have focused on maternal positivity and resilience as mitigating factors for stress in caregivers of children with ID. Maternal positivity can help to moderate the stress experienced by caregivers as a result of child behaviour problems (Jess et al., 2018). There is evidence of the interaction between the caregiver's mental and emotional wellbeing and the manner in which they parent (Fenning & Baker, 2012). Poor parental responses and tenuous relationships between parent and child can have a negative impact on the child's ability to reach their full developmental potential (Peer & Hillman, 2012).

Depression is projected to be the greatest global burden of disease by 2030 (Mathers & Loncar, 2006) and it is therefore crucial to address caregiver depression and focus on improving mental health. When looking at the broader issue of mental health in South Africa, there is a strong movement to diagnose common mental health illnesses early so that appropriate treatment can be implemented. Investment in early diagnosis and intervention results in positive economic outcomes as individuals are treated at a primary level rather than left undiagnosed, vulnerable and unproductive (Stein, Sordsdahl & Lund, 2018).

1.5 Caregiver anxiety (HADS A)

Contrary to findings from other studies which show higher levels of anxiety in caregivers of children with disabilities, this study found that the scores for anxiety were not statistically different between the two groups. Both groups had elevated scores for anxiety on this scale. Anxiety and mood disorders are more common in women than in men and the majority of the participants in this study were women. This may explain similar reports of anxiety in both groups. In addition, studies have shown that the South African population has a high prevalence of anxiety and mood disorders when compared to populations in other countries (Herman et al., 2009). The high figure deserves further attention as it has implications for all carer-child dyads and wellbeing but especially those carers whose children have intellectual and developmental disabilities. Moreover, the parent distress subscale of the PSI is confounded by the dyadic relationship between caregiver and child. The HADS does not isolate child factors that impact stress but rather measures caregiver specific anxiety and depression components of stress.

1.6 Access to resources

Many caregivers showed interest in knowing more about children's behaviour as well as acquiring information about Intellectual disabilities indicating a need for supportive services for children with intellectual and developmental disabilities and behavioural difficulties. There are existing community-based resources available to the study cohort, which offer information and support for various disabilities - however, the caregivers in this study did not report making use of them. It may be beneficial to explore the reasons why the caregivers do not make use of the existing services by various NGOs and then address these to make use of the resources which are readily available. It should be noted that many of the organisations rendering support services do so for a specific disability for instance Autism Spectrum Disorder and Down Syndrome. Assisting caregivers in managing difficult behaviours in their children may have a positive impact on their own mental well-being and that of the child. Service point-of-contact opportunities could be explored to provide such information and behavioural support. Findings by a systematic review done by South African authors Hohlfeld, Harty & Engel (2018) support the implementation of caregiver training programmes as a behavioural intervention strategy for children with ID. It should be noted that relief in the form of financial or material resources may be a primary need for many caregivers of dependent children with ID; however, in order to have an impact on caregiving-related stress, evidence-based, accessible and scalable behavioural supports and interventions ought to form part of the service response.

There is strong evidence of positive benefits of early intervention in children with developmental disabilities and the effects are well described. Early intervention programmes have been shown to improve caregiver confidence and optimism which in turn positively impacts the developmental, social and functional outcomes in the child with ID (Guralnick, 2017). Specifically, it is important to address the behaviour difficulties at an early life stage as young children with ID and unmet behavioural support needs, may grow up to become adolescents and adults with challenging behaviour, requiring costly, specialised long-term treatment and interventions. Although a costing review has been undertaken in South Africa for timeous interventions in adults with mental health problems (Petersen &

Lund, 2011), there are longitudinal data to show the benefits of early interventions for children with developmental disabilities, who are at a higher risk than the general population for adverse long-term behavioural and mental health outcomes.

Across South Africa, including in the Western Cape, services for child behaviour support and intervention are considered a tertiary level function rather than that of the primary, or basic level of care, such as the community and even regional health facilities. International studies have described similar problems where there is a narrow range of services available to children with ID, as well as these being difficult to access (Bhatia et al., 2015; Cramm & Nieboer, 2011; McConnell et al., 2014). In South Africa, there is an overall lack of service resources for people with all disabilities within the government sector and many services are by default, rendered by Non-governmental organisations (Adnams, 2010; McKenzie & McConkey, 2016).

1.7 Correlation and regression analysis outcomes

Correlation analysis showed that for both caregiver groups, there was no significant association between carer or child demographic factors and caregiver reported stress scores measured by the PSI scale; nor between the demographic variables and HADS depression or anxiety scores. In contrast, there was a statistically significant association between three measures of the behaviours rated on the ABC and caregiver depression. Regression analysis showed that in caregivers of children with ID, hyperactive behaviour is a significant predictor of caregiver depression. There was a statistically significant correlation of the PSI subscale Parent Distress, carer depression and anxiety which is to be expected due to the complexity and overlap of these clinical conditions. The PSI subscales of Parent-Child Dysfunction and Difficult child were confounding due to the individual items in these PSI subscales rating the same child behaviours were rated in the ABC questionnaire. Although demonstration of a causal effect in the association of child behaviour and caregiver stress and depression is beyond the scope of this study, the relationship between caregiver stress and child behaviour is likely bi-directional, in that the one impacts on the other. In their study, McConnell et al. (2014) describe the same bi-directional relationship and describe how child behaviour can impact on caregiver stress which may invoke negative parenting styles—which in turn may result in an increase in challenging behaviour from the child. Future studies could examine the direction of this association and other factors influencing this relationship in South African settings.

In addition, knowledge of the specific patterns of behaviours that challenge caregivers (such as hyperactive behaviours) may also determine the type of supports, services and behavioural interventions needed. This may better inform person-centred services and resources to meet the needs of caregivers in order to support their children with ID.

2. Limitations of the study

The participants' children have access to clinical services at the RCWMCH NDC, a tertiary health service. This study therefore may not reveal potential associations between levels of stress and lack of access to resources and services. In other words, the results may not be generalizable to caregivers whose children do not access services, and specialist services in particular.

Findings may not be generalisable to the broader population outside of the Cape metropolitan area and Western Cape Province. The study was conducted in a tertiary health facility setting. Further research is necessary within other service settings in other geographical areas to establish whether the findings are applicable to the Western Cape and other national regions.

Participants who could not communicate in English or Afrikaans were to be excluded from the study. This however was not necessary as all participants were able to communicate sufficiently in English.

The findings of this study which were not significant may be a reflection of the power of the study due to the low number of participants. The only way to ascertain whether this is the case is to repeat the study with larger numbers and include a broader population sample.

The data in this study were obtained from the caregiver's subjective responses to questionnaires administered by the researcher rather than through observed, objective measures.

This study focused on negative attributes and not on resilience and positivity which are mitigating factors for stress and depression and may have had implications for intervention.

3. Conclusion

To the author's knowledge, this is the first South African study to investigate child behaviour and carer stress, anxiety and depression in one cohort, albeit in a convenience, clinic sample. The results show that higher behaviour scores were correlated with higher scores for stress and depression. In particular, hyperactive behaviour was a child factor predictor for depression in caregivers of children with ID. A further significant finding was the high rate of caregivers of children with ID who reported being in the clinical range for depression. This study highlighted the need for services available to children with ID in the form of behavioural interventions and for caregivers in the form of support and information. These findings are relevant with regards to implications for specialised and general services and resources to support caregivers in meeting their children's behavioural needs which in turn will support their own mental health.

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Appendix A: Questionnaires

Demographic Questionnaire

RCWMCH caregiver stress study

Place Child’s Red Cross Sticker Here

Please circle the appropriate number that corresponds to your answer, alternatively write your answer in the block available next to the question.

Participant Name:	Date of assessment:	Study No:

Caregiver information		
1. Age or D.O.B		
2. Sex	Female	**1**
	Male	**2**
3. South African Citizen/S.A.ID	Yes	**1**
	No: ______________________________	**2**
4. Home Language	English	**1**
	Afrikaans	**2**
	IsiXhosa	**3**
	Other: ________________________	**4**
	Mixed	**5**
5. Relationship to Child	Birth Mother	**1**
	Birth Father	**2**
	Grandparent	**3**
	Sibling	**4**
	Neighbour	**5**
	Other family member:_________________	**6**
	Other: _____________________________	**7**
5.a If other, is this a formal placement (court order) or informal placement?	Informal Placement	**1**
	Foster care	**2**

	Adoption	**3**
	Other: ________________________	**4**
6. Own relationship status	Married	**1**
	Single / Divorced	**2**
	Live with partner	**3**
	In a relationship, living separately	**4**
7. Do you receive support from your family or close friends/ partner?	Financial	**1**
	Emotional/Talking support	**2**
	No (receive no support)	**3**
7.a.) if yes, who?	Mother	**1**
	Father	**2**
	Sibling	**3**
	Grandparents	**4**
	Partner	**5**
	Neighbour	**6**
	Friend	**7**
	Other:________________________________	**8**
8. Education	Last education completed/Last grade passed:	
	No formal schooling	**1**
	Primary school grade _________	**2**
	Secondary school grade ________	**3**
	Post-secondary school no. of years ________	**4**
9. Employment status	Employed	**1**
	Unemployed	**2**
	Self-employed	**3**
	Part-time / casual worker	**4**
	Retired (pensioner)	**5**
10. Have you ever had to leave your employment to stay at home to care for your child because of his or her disability?	Yes	**1**
	No	**2**
	N/A (child is not disabled)	**3**
11. How many people live in your household?		
12. SASSA Grants received within your household that support you and your child	Care Dependency Grant	**1**
	Child Support Grant	**2**
	Disability Grant	**3**
	Older Persons Grant (pension)	**4**
	Foster Care Grant	**5**
	Grant in Aid	**6**
	None	**7**

13. How many dependants do you have?		
14. Do you have financial difficulties that affect the care of the child?	Yes No	**1** **2**
15. Do you suffer from any chronic illness/es	Yes No	**1** **2**
14.a) If yes, which illnesses?	Diabetes High Blood Pressure Asthma / other lung condition HIV/AIDS Physical Disability Mental Illness Other: ____________________	**1** **2** **3** **4** **5** **6** **7**
16. How long does it take you to travel from home to RCWMCH in minutes?		
17. Do you experience difficulties in transport or travelling due to your child's disability? (If yes, briefly detail)	No Yes: ________________________________ N/A (child not disabled)	**1** **2** **3**
18. How many appointments and / or admissions have you had at RCWMCH in the last 6 months?	Appointments Admissions	
19. Do you attend other Hospitals or CHCs? Eg. When your child is sick. If yes, how many appointments and / or admissions in the last 6 months? 18 and 19, for all causes	No Yes Which Clinics: _____________________________	**1** **2**
20. Do you find it difficult to attend the hospital or CHC appointments?	Yes No Sometimes	**1** **2** **3**
21. Do you access professional resources or support services outside of this clinic?	Down Syndrome Support Cape Autism Western Cape WC Cerebral Palsy Association Cape Mental Health Hope House Childline Department of Social Development Inclusive Education SA FAMSA Child and Adolescent P&MH Unit (RXH, Lentegeur, Tygerberg)	**1** **2** **3** **4** **5** **6** **7** **8** **9** **10**

	Parent Centre	**11**
	WCFID	**12**
	Department of Education	**13**
	CHCs	**14**
	Other: _________________________	**15**
	None	**16**
22. Has a family member or someone in your community teased or harmed your child?	No	**1**
	Yes: _____________________________	**2**
23. Do you have concerns about the safety of your child?	No	**1**
	Yes: _____________________________	**2**
24. Do you as the caregiver feel that you need or would like more information on intellectual disability and Developmental Disabilities?	Yes	**1**
	No	**2**
	N/A (child does not have ID)	**3**
25. Do you as the caregiver feel that you need or would like more information on children's difficult behaviour and how to manage it?	Yes	**1**
	No	**2**
Child Information		
Child's Name	**RXH Folder No.**	
1. Age or D.O.B	Clinic attended today:	
2. Gender:	Male	**1**
	Female	**2**
3. Home Language	English	**1**
	Afrikaans	**2**
	IsiXhosa	**3**
	Other: __________________________	**4**
4. Is the child a South African Citizen	Yes	**1**
	No: _____________________________	**2**
5. Level of Child's Intellectual Disability (may circle two if given as e.g. borderline mild/moderate)	None	**1**
	Borderline	**2**
	Mild	**3**
	Moderate	**4**
	Severe	**5**
	Profound	**6**
6. Does the child have any other developmental or health condition (comorbidities)? *behaviour that is challenging or is difficult to manage	ASD	**1**
	ADHD	**2**
	Epilepsy	**3**
	Allergies / asthma	**4**
	Challenging behaviour	**5**
	Hearing impairment	**6**

	Visual impairment	**7**
	Language Delay other than ID	**8**
	Cerebral Palsy	**9**
	Other motor disability	**10**
	FASD	**11**
	Genetic Syndrome: _______________	**12**
	Other condition:__________________________	**13**
	None	**14**
7. Education Status	Informal Creche	**1**
	Registered ECD	**2**
	Mainstream School (Grade______)	**3**
	Special Education School (Grade_____)	**4**
	Special Care Centre	**5**
	None (at home)	**6**
	Residential Centre	**7**
	Awaiting placement	**8**

Aberrant Behaviour Checklist (ABC) - community

RCWMCH caregiver stress study

Participant Name:	Date of assessment:	Study No:

RATING

0 = not at all a problem
1= the behaviour is a problem but slight in degree
2 = the problem is moderately serious
3= the problem is severe in degree

Do not spend too much time on each item - your first reaction is usually the right one

1. Excessively active at home, school, work, or elsewhere	0	1	2	3
2. Injures self on purpose.	0	1	2	3
3. Listless, sluggish, inactive	0	1	2	3
4. Aggressive to other children or adults (verbally or physically)	0	1	2	3
5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3
11. Stereotyped behaviour; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behaviour	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3

20. Fixed facial expression; lacks emotional responsiveness	0	1	2	3
21. Disturbs others	0	1	2	3
22. Repetitive speech	0	1	2	3
23. Does nothing but sit and watch others	0	1	2	3
24. Uncooperative	0	1	2	3
25. Depressed mood	0	1	2	3
26. Resists any form of physical contact	0	1	2	3
27. Moves or roles head back and forth repetitively	0	1	2	3
28. Does not pay attention to instructions	0	1	2	3
29. Demands must be met immediately	0	1	2	3
30. Isolates himself/herself from other children or adults	0	1	2	3
31. Disrupts group activities	0	1	2	3
32. Sits or stands in one position for a long time	0	1	2	3
33. Talks to self loudly	0	1	2	3
34. Cries over minor annoyances and hurts	0	1	2	3
35. Repetitive hand, body, or head movements	0	1	2	3
36. Mood changes quickly	0	1	2	3
37. Unresponsive to structured activities (does not reacts)	0	1	2	3
38. Does not stay in seat (e.g., during lesson or training periods, meals, etc.).	0	1	2	3
39. Will not sit still for any length of time	0	1	2	3
40. Is difficult to reach, contact, or get through to	0	1	2	3
41. Cries and screams inappropriately	0	1	2	3
42. Prefers to be alone	0	1	2	3
43. Does not try to communicate by words or gestures	0	1	2	3
44. Easily distractible	0	1	2	3
45. Waves or shakes the extremities repeatedly	0	1	2	3
46. Repeats a word or phrase over and over	0	1	2	3
47. Stamps feet or bangs objects or slams doors	0	1	2	3
48. Constantly runs or jumps around the room	0	1	2	3
49. Rocks body back and forth repeatedly	0	1	2	3
50. Deliberately hurts himself/herself	0	1	2	3
51. Pays no attention when spoken to	0	1	2	3
52. Does physical violence to self	0	1	2	3
53. Inactive, never moves spontaneously	0	1	2	3
54. Tends to be excessively active	0	1	2	3
55. Responds negatively to affection	0	1	2	3

56. Deliberately ignores directions	0	1	2	3
57. Has temper outbursts or tantrums when he/she does not get his/her own way	0	1	2	3
58. Shows few social reactions to others	0	1	2	3

ABC SCORE SHEET

Subscale I *(Irritability)*	*Subscale II* *(Lethargy)*	*Subscale III* *(Stereotypy)*	*Subscale IV* *(Hyperactivity)*	*Subscale V* *(Inappropriate Speech)*
2__________	3__________	6__________	1__________	9__________
4__________	5__________	11__________	7__________	22__________
8__________	12__________	17__________	13__________	33__________
10__________	16__________	27__________	15__________	46__________
14__________	20__________	35__________	18__________	
19__________	23__________	45__________	21__________	
25__________	26__________	49__________	24__________	
29__________	30__________		28__________	
34__________	32__________		31__________	
36__________	37__________		38__________	
41__________	40__________		39__________	
47__________	42__________		44__________	
50__________	43__________		48__________	
52__________	53__________		51__________	
57__________	55__________		54__________	
	58__________		56__________	

Total *I*_______	Total *II*______	Total *III*______	Total *IV*_______	Total *V*_______

Interpretation:

A:	0 -11	0 -12	0 -5	0-12	0 - 3
B	12-23	13-25	6-10	13-25	4 - 6
C	24-34	26-37	11-15	26-37	7 - 9
D	35-45	38-48	16-21	38-48	10-12

A= No problems

B= Mild problems

C= Moderate problems

D= Severe problems

The Parenting Stress Index-Short Form

RCWMCH caregiver stress study

Circle the number corresponding to the answer that best describes how you have been feeling about this child, or have been feeling since the child has been in your care. Do not take too long to think about the answers as the first thought is usually the most accurate.

Participant Name:	Date of assessment:	Study No:

1. I often have the feeling that I cannot handle things very well	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
2. I find myself giving up more of my life to meet my child's needs than I ever expected.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
3. I feel trapped by my responsibilities as a parent.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
4. Since having my child I have been unable to try new and different things.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
5. Since having my child I feel that I am almost never able to do things that I like to do.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
6. I am unhappy with the last purchase of clothing I made for myself.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
7. There are quite a few things that bother me about my life.	Strongly agree Agree	**5** **4**

	Not sure Disagree Strongly disagree	**3** **2** **1**
8. Having a child has caused more problems than I expected in my relationship with my spouse.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
9. I feel alone and without friends.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
10. When I go to a party I usually expect not to enjoy myself.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
11. I am not as interested in people as I used to be.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
12. I don’t enjoy things as I used to.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
Total score Parental Distress sub-scale:		
13. My child rarely does things for me that make me feel good.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
14. Most time I feel that my child does not like me and does not want to be close to me.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
15. My child smiles at me much less than I expected.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
16. When I do things for my child, I get the feeling that my efforts are not appreciated very much.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
17. When playing, my child doesn’t	Strongly agree	**5**

often giggle or laugh.	Agree Not sure Disagree Strongly disagree	**4** **3** **2** **1**
18. My child doesn't seem to learn as much as most children.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
19. My child is not able to do as much as I expected.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
20. My child doesn't seem to smile as much as most children.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
21. It takes a long time and it is really hard for my child to get used to new things.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
22. I feel that I am a person who has some trouble being a parent	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
23. I expected to have closer and warmer feelings for my child than I do and this bothers me.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
24. Sometimes my child does things that bother me just to be mean.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
Total score for Parent-Child Dysfunctional Interaction sub-scale:		
25. There are many things that my child does that really bother me.	Strongly agree Agree Not sure Disagree Strongly disagree	**5** **4** **3** **2** **1**
26. My child generally wakes up in a bad mood.	Strongly agree Agree Not sure Disagree	**5** **4** **3** **2**

	Strongly disagree	**1**
27. I feel that my child is very moody and easily upset.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
28. My child does a few things that bother me a great deal.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
29. My child reacts very strongly when something happens that my child doesn't like.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
30. My child gets upset easily over the smallest thing.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
31. My child's sleeping and eating schedule was much harder to establish than I expected.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
32. I have found that getting my child to do something or to stop doing something is much harder than I expected.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
33. My child turned out to be more of a problem than I expected.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
34. My child makes more demands on me than most children.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
35. My child seems to cry more often than most children.	Strongly agree	**5**
	Agree	**4**
	Not sure	**3**
	Disagree	**2**
	Strongly disagree	**1**
Total score for Difficult Child sub-scale:		

Hospital Anxiety and Depression Scale

RCWMCH caregiver stress study

Circle the number corresponding to the answer that best describes how you have been feeling in the last WEEK. Do not take too long to think about the answers as the first thought is usually the most accurate.

Participant Name:	Date of assessment:	Study No:

A 1. I feel tense or wound up	Most of the time	**3**
	A lot of times	**2**
	From time to time	**1**
	Not at all	**0**
D 2. I still enjoy the things I used to	Definitely as much	**0**
	Not quite so much	**1**
	Only a little	**2**
	Hardly at all	**3**
A 3. I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	**3**
	Yes, but not too badly	**2**
	A little, but it doesn’t worry me	**1**
	Not at all	**0**
D 4. I can laugh and see the funny side of things	As much as I always could	**0**
	Not quite as much now	**1**
	Definitely not so much now	**2**
	Not at all	**3**
A 5. Worrying thoughts go through my mind	Most of the time	**3**
	A lot of times	**2**
	From time to time	**1**
	Only occasionally	**0**
D 6. I feel cheerful	Most of the time	**0**
	Usually	**1**
	Not often	**2**
	Not at all	**3**
A 7. I can seat at ease and feel relaxed	Definitely	**0**
	Usually	**1**
	Not often	**2**

	Not at all	**3**
D 8. I feel as I am slowed down	Nearly all the time Very often From time to time Not at all	**3** **2** **1** **0**
A 9. I get a sort of frightened feeling like butterflies in the stomach	Not at all From time to time Quite often Very often	**0** **1** **2** **3**
D 10. I have lost interest in his appearance	Definitely I don't take so much care as I should I may not take quite as much care I take just as much care as ever	**3** **2** **1** **0**
A 11. I feel restless, as if I had to be on the move	Very much indeed Quite a lot Not very much Not at all	**3** **2** **1** **0**
D 12. I look forward with enjoyment to things	As much as I ever did A little less than I used to Definitely less than I used to Not at all	**0** **1** **2** **3**
A 13. I get a sudden feeling of panic	Very often indeed Quite often From time to time Not at all	**3** **2** **1** **0**
D 14. I can enjoy a good tv or radio program or book	Often Sometimes Not often Hardly at all	**0** **1** **2** **3**

Total A:
Total B:
Total Score:

Appendix B: Consent Form

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Groote Schuur Hospital J-Block
Anzio Road
Observatory 7925
Cape Town
South Africa
Telephone: +27 21-404-2137
Fax: +27 21-448-8158

Date:

Dear Parent/Caregiver,

Ms Sarah Strachan from the University of Cape Town is doing a study with the parents and caregivers who attend the Neurodevelopmental and Cerebral Palsy Clinics. This study aims to explore the experiences of parents and caregivers who care for their child who has intellectual disability. Another name used for intellectual disability is developmental delay. The information gained from parents and caregivers will help us understand your experiences and any challenges in caring for your child.

In order to better understand the experiences of carers of children with intellectual disabilities, a group of carers whose children do not have intellectual disability, will be included in the study as a comparison.

I am asking your permission for an interview which involves answering questions about yourself, such as your age and where you live. You will also be asked questions about your experiences as your child's caregiver and about the child's behaviour. The interview will last approximately 30 minutes and be undertaken by myself, Ms Sarah Strachan.

There may or may not be a benefit to you by taking part in the interview. Your participation is strictly voluntary. You may choose to answer only questions with which you feel comfortable. You may stop the interview at any time. If personal, health or other information is shared during the interview for which you may wish to seek assistance, we will make the necessary contacts with relevant services. If you decide to withdraw from the interview, this will not affect your care at this hospital and all information collected will be destroyed. It is hoped that the information you provide may assist in gaining knowledge about the right kind of psychological or emotional support that can help carers of children with intellectual disability who attend health services.

All information you give will be confidential and will be kept securely in a locked office. Your name will not be directly connected to any information you provide and your information will be identified by a study number.

If you have any questions about this study, you may contact the researchers or the University of Cape Town any time during the study.

Contact telephone numbers: (during office hours)
Prof Colleen Adnams (research team): 083 284 6703 email colleen.adnams@uct.ac.za

Your signature below means that you have decided to take part in the interview and that that you have read (or were read) the information provided above. If you have further questions before signing, the researcher will discuss these with you. You will receive a copy of the signed form.

Thank you

Yours Sincerely,

Ms Sarah Strachan

CONSENT FORM

I (name) ____

the parent / legal guardian or main (primary) carer of (name of child)

____

give permission to take part in an interview about my experiences of caring for (name of

child) ____________________ and about his / her behaviour

Address:____Postal Code:
____

Contact tel: number: ____

Signature of parent / carer

____Date:________________

Signature of witness
(researcher):________________________________Date:________________