Exploring Caregivers' and Health Workers' Perceptions on the Effects of Caregiver-child Separation during Long-term Hospitalisation for MDR-TB in the Western Cape: A Qualitative Study

by

Kyla Amy Meyerson

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Supervisor: Prof. Mark Tomlinson Co-supervisor: Dr. Graeme Hoddinott

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Declaration

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Abstract

There are an estimated 32 000 incident cases of multidrug-resistant tuberculosis (MDR-TB) in children globally each year. Between 2011 and 2013, 323 children were diagnosed with TB at the Western Cape regional TB referral hospital and of these children, 4.7% had MDR-TB. MDR-TB treatment requires extended hospitalisation which currently entails caregiver-child separation. Caregiver-child separation has been shown to cause behavioural and emotional problems in children. I explored caregivers' and health workers' perceptions of the effects of caregiver-child separation during long-term hospitalisation for MDR-TB treatment. I conducted 19 semi-structured, in-depth interviews with caregivers and health workers of children (aged zero to five years) who were receiving hospital-based treatment for MDR-TB. All interviews were audio-recorded, transcribed and translated verbatim. I used Braun and Clarke's guidelines for thematic analysis to organise and interpret the data. I identified three major themes: (i) MDR-TB treatment was a distressing experience; (ii) children's behavioural and emotional states included excessive crying, aggression, hyperactivity, and withdrawal; (iii) caregivers' and health workers' used behavioural and emotional management strategies such as deception, threat, and prioritisation of biomedical health over psychological health. This study highlights the challenges that children, caregivers and health workers experienced in the context of caregiver-child separation during MDR-TB treatment. These problems are mostly likely the result of a complex interplay between factors such as caregiver-child separation, long-term hospitalisation, social adversity together with other predisposing factors. Future research should test the effectiveness of an intervention to reduce the negative effects of caregiver-child separation during MDR-TB treatment on children, caregivers and health workers in the Western Cape.

Keywords: paediatric MDR-TB, caregiver-child separation, long-term hospitalisation, attachment

Opsomming

Daar is na beraming 32 000 nuwe gevalle van veelvoudige middelweerstandige-TB (MDR-TB) onder kinders wêreldwyd elke jaar. Tussen 2011 en 2013 was daar 323 kinders met TB gediagnoseer by die Wes-Kaapse TB verwysing hospitaal, waarvan 4.7% MDR-TB gehad het. Behandeling vir MDR-TB vereis verlengde hospitalisasie wat tans versorger-kind skeiding behels. Versorger-kind skeiding het al getoon om gedrags en emosionele probleme in kinders te veroorsaak. Ek het versorgers en gesondheidswerkers se sieninge oor die effekte van versorger-kind skeiding verken gedurende langtermyn hospitalisasie vir behandeling van MDR-TB. Ek het 19 semi-gestruktureerde, in-diepte onderhoude gevoer met die versorgers en gesondheidswerkers van kinders (zero tot vyf jaar oud) wat behandeling in die hospitaal ontvang het vir MDR-TB. Al die onderhoude was met ‘n oudioband opgeneem, getranskribeer and verbatim vertaal. Ek het Braun en Clarke se riglyne vir tematiese analise gebruik om die data te organiseer en te interpreteer. Ek het drie hooftemas geïdentifiseer: (i) MDR-TB behandeling was ‘n traumatiese ervaring; (ii) kinders se gedrag and emosionele toestande gedurende MDR-TB behandeling het oormatige huilery, aggressie, hiperaktiwiteit, en onttrekking ingesluit; (iii) versorgers en gesondheidswerkers se gedrag en emosionele bestuurstrategië het misleiding, dreiging, en die prioritisering van bio-mediese gesondheid oor sielkundige gesondheid ingesluit. Hierdie studie beklemtoon die uitdagings wat kinders, versorgers en gesondheidswerkers ervaar in die konteks van versorger-kind skeiding, gedurende MDR-TB behandeling. Hierdie probleme is waarskynlik die gevolg van komplekse interaksie tussen faktore soos kind-versorger skeiding, lang termyn hospitalisasie, sosiale teenstrydigheid tesame met ander pridisponerende faktore. Toekomstige navorsing moet verder verken of ‘n intervensie wat versorger-kind verhoudings priotiseer gedurende MDR-TB behandeling die ontwikkeling van gedrag en emosionele probleme kan voorkom in

kinders en of dit versorgers en gesondheidswerkers se gebruik van beperkende versorg strategië kan verhoed.

Sleutelwoorde: pediatriese MDR-TB, versorger-kind skeiding, langtermyn hospitalisasie, gehegtheid

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Acronyms and Abbreviations

DR-TB: Drug-resistant tuberculosis

DTTC: Desmond Tutu TB Centre

MDR-TB: Multidrug-resistant tuberculosis

MDR-PK II: A research study conducted at DTTC. The study is a prospective, longitudinal observational pharmacokinetic study in HIV-infected and uninfected children aged 0-17 years who are receiving routine treatment for drug-resistant tuberculosis with moxifloxacin, levofloxacin, or linezolid.

TB: Tuberculosis

UK: United Kingdom

WHO: World Health Organization

Chapter 1: Introduction

1.1 Background and Rationale

1.1.1 MDR-TB in the Western Cape. Drug-resistant tuberculosis (DR-TB) is considered a public health crisis (World Health Organization [WHO], 2013). Multidrug-resistant tuberculosis (MDR-TB) is a tuberculosis (TB) infection caused by bacteria that are resistant to Isoniazid and Rifampicin which are two out of a total of four of the most effective first line anti-TB medications (WHO, 2014). An estimated 558 000 people developed rifampicin-resistant TB in 2017. Of these people, 82% had MDR-TB (WHO, 2018). Using statistical modelling techniques, Jenkins and colleagues (2014) estimated a global childhood (0 to 15 years) MDR-TB incidence of 32 000 in 2010.

The Western Cape has a high paediatric MDR-TB burden (Schaaf, Garcia-Prats, Preez, Rautenbach, & Hesseling, 2016). In 2012, there were 47 849 cases of TB in the Western Cape. Of these cases, 4 877 (10%) were children below five years (Garcia-Prats, 2016). Between 2011 and 2013, 323 children below 13 years were diagnosed with active TB disease at the regional TB referral hospital (Tygerberg Children's Hospital) and of these children, 4.7% had MDR-TB (Schaaf et al., 2016).

Treatment of paediatric MDR-TB requires second-line anti-tuberculosis medications, (Ettehad, Schaaf, Seddon, Cooke, & Ford, 2012; Seddon, Hesseling, Willemse, Donald, & Schaaf, 2012). Second-line treatment is less effective and more toxic than first line anti-TB medications (WHO, 2014). Most MDR-TB drugs are unpalatable and children using the drugs experience numerous side effects including nausea, vomiting, and diarrhoea (Marais & Schaaf, 2010; Seddon, Hesseling, Marais, et al., 2012). However, children with MDR-TB have a good prognosis if treatment is started early and there is continuity of care (Seddon, Hesseling, Godfrey-Faussett, & Schaaf, 2014).

In the Western Cape, children with MDR-TB receive community-based care with regular follow-up appointments at Tygerberg Children's Hospital (TCH). Alternatively, children are admitted to Brooklyn Chest Hospital (BCH), a specialist TB hospital, for the initial part of treatment (six months of daily injections). After discharge from BCH, the children receive community-based care with regular follow-up appointments at TCH (Franck et al., 2014; Seddon et al., 2014; WHO, 2008). However, children with MDR-TB can be hospitalised for more than six months and up to three years, often due to disorganised home environments in which adherence is anticipated to be poor (Franck et al., 2014; SA Medical & Education Foundation, 2012). As a result, children with MDR-TB may experience separation from their caregivers for extended periods.

1.1.2 Early studies on mother-child separation. Research on the effects of mother-child separation began in the 1940s with the work of John Bowlby (Senior, 2009). Bowlby observed the long-term effects on children who had been separated from their mothers due to wartime evacuation programmes (Jarvis, Swiniarski, & Holland, 2016). Later, members of the WHO commissioned Bowlby to write a report on the psychological health of children who were orphaned after World War II. Bowlby (1951) concluded that early disruptions in the mother-child relationship might lead to the development of psychopathologies or behavioural and emotional problems.

Bowlby formulated attachment theory based on his extrapolations from early findings. Bowlby (1969) suggested that children form an emotional bond, or attachment, with a primary caregiver in order to survive. Bowlby (1953, 1979) argued that a child must experience a consistent, warm, and sensitive relationship with a primary caregiver in order to develop into a psychologically healthy adult. However, a disruption in the attachment bond between an infant and their caregiver, before the age of five years, that is prolonged, or without an alternative emotional substitute, could result in long-term emotional and social

difficulties (Bowlby, 1953; Van der Horst, 2011). This vulnerable group (children in the age category of zero to five years) was the focus of this study.

Attachment theory is still recognised as a valuable contribution to understanding caregiver-child separation (Holmes, 2014). However, it is unclear whether attachment theory is applicable in understanding how children respond to separation during long-term hospitalisation for MDR-TB in the Western Cape.

1.1.3 Caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape. To the best of my knowledge, Franck and colleagues (2014) and Loveday and colleagues (2018) are the only studies to explore caregivers' perceptions of the psychological impact of MDR-TB treatment in the South African context (in the Western Cape and KwaZulu-Natal, respectively). Participants in these studies reported that children developed behavioural and emotional problems during MDR-TB treatment. In addition, Franck and colleagues (2014) and Loveday and colleagues (2018) listed elements of MDR-TB treatment that might have contributed to children's development of behavioural and emotional problems. Loveday and colleagues (2018) highlighted caregiver-child separation as a potential factor contributing to children's development of behavioural and emotional problems. Franck and colleagues (2014) explored caregivers' and children's experiences of MDR-TB treatment more generally but did not focus on caregiver-child separation due to long-term hospitalisation for MDR-TB. Therefore, there is no literature in the Western Cape that explores caregiver-child separation in the context of long-term hospitalisation for MDR-TB.

1.2 Research Aim

I aimed to explore caregivers' and health workers' perceptions of the effects of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.

1.3 Research Objectives

i. To describe caregivers' perceptions of the effects of caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.

ii. To describe health workers' perceptions of the effects of caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.

1.4 Overview of Chapters

In chapter two, I critically review the literature on caregiver-child separation. Specifically, I explore early studies on mother-child separation with a focus on the work of Bowlby. I review non-maternal care and caregiver-child separations in different contexts: institutionalisation, day-care, and hospitalisation. Thereafter, I examine health workers' and caregivers' interpretations of children's responses to caregiver-child separation. The chapter concludes by expanding on the research on caregiver-child separation due to MDR-TB treatment in South Africa.

I describe the methodology I adopted in this study in chapter three; including the research design and setting, how I selected my sample, and how I collected and analysed my data. Additionally, I explain the way in which I maintained ethical principles and enhanced the trustworthiness of the data.

I highlight the three themes that I found using thematic analysis in chapter four. Additionally, I present a reflexive piece, in which I critically reflect on how my life perspective and context influenced how I conducted the research, and how it may have biased my interpretation of the findings. Thereafter, I explain what I did to manage this throughout the research process.

In chapter five, I discuss the relevance of my findings for understanding caregiver-child separation in the context of long-term hospitalisation for MDR-TB, as well as

attachment theory and MDR-TB treatment more generally. Specifically, I explore whether existing literature supports or contradicts my findings. Additionally, I discuss the strengths and limitations of my study and the impact this may have had on my findings. Thereafter, I present possible directions for future studies and recommendations for policies. Finally, I offer my overall conclusions.

Chapter 2: Literature Review

2.1 Introduction

In this chapter, I introduce John Bowlby's attachment theory as the theoretical framework for the current study. Thereafter I critically review research on caregiver-child separation by exploring research in the following areas:

i. Bowlby's early studies on mother-child separation;
ii. non-maternal care;
iii. children's responses to caregiver-child separations in different contexts: institutions, day-cares, and hospitals;
iv. health workers' and caregivers' interpretations of children's responses to caregiver-child separation; and
v. caregiver-child separation due to MDR-TB treatment in South Africa.

In this review, I highlight that, according to attachment theory, children who are separated from their caregivers due to long-term hospitalisation are at risk of developing long-term behavioural and emotional problems. I indicate that, given the high paediatric MDR-TB burden, there is insufficient research in the Western Cape that explores caregiver-child separation due to long-term hospitalisation for MDR-TB. I also explore the relevance of attachment theory to the context of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.

2.2 Theoretical Framework

Attachment theory, advanced by John Bowlby, serves as the theoretical framework to explore caregivers' and health workers' perceptions of the effects of caregiver-child separation in the context of long-term hospitalisation. In this section, I outline some of the assumptions of attachment theory.

Infants and young children have an innate tendency to form an attachment, or emotional bond, with a primary caregiver (Bowlby, 1969). Infants and young children exhibit behaviours such as crying, clinging, or smiling, in order to restore proximity to their caregiver or to alert their caregiver's attention to calm their distress (Bowlby, 1969). These behaviours serve as an adaptive strategy for infants and young children who are born unable to care for themselves (Bowlby, 1969; Gillath, Karantzas, & Fraley, 2016).

As infants and young children grow older, they increasingly target their attachment behaviours at a specific caregiver – an attachment figure (Bowlby, 1969). If the attachment figure responds to their signals, they experience a sense of security (Bowlby, 1969). However, if the attachment figure does not respond to their attachment behaviours, they will experience grief and mourning (Bowlby, 1960). For Bowlby (1951, 1979) infants and young children must experience a consistent, warm, and sensitive relationship with a primary caregiver in order for them to develop into psychologically healthy adults. However, a disruption in the attachment bond between an infant or a young child and his/her caregiver that is prolonged, or without an alternative emotional substitute, could result in long-term emotional and social difficulties (Bowlby, 1953).

In addition, the organisation of the infant and young child's attachment relationship with their primary caregiver forms the foundation of their internal working model (Bowlby, 1980). An internal working model is a cognitive framework through which infants and young children interpret the world, themselves and others (Jarvis, 2004). Bowlby's colleague, Mary Ainsworth, contributed to the development of attachment theory and specifically, internal working models by coining the term "attachment styles" (Ainsworth & Bell, 1970). Attachment styles are infant and young children's patterns of attachment behaviours targeted at the primary caregiver. Ainsworth identified three attachment styles (secure, insecure-ambivalent and insecure-avoidant) based on her experimental procedure the "Strange

Situation" (see for example, Ainsworth and Bell, 1970, and Ainsworth, Blehar, Waters, and Wall, 1978, for further information on the Strange Situation procedure). Later, Ainsworth's student, Mary Main, added a fourth attachment style known as "disorganised attachment" (Main & Solomon, 1990).

According to Ainsworth (1970), an attachment style reflects the history of the infant and young child's interactions with their caregivers. Specifically, infants and young children develop a secure attachment when their caregivers respond to their needs sensitively, responsively and consistently. Inconsistent and insensitive caregiving typically predicts an insecure-ambivalent attachment style whereas an insecure-avoidant attachment style is usually associated with caregiving characterised by insensitivity, intrusiveness and rejection. It is often the case that caregivers of infants and young children with a disorganised attachment had previous experiences of abuse or neglect (Newton, 2008) and as a result, these caregivers typically use hostile and intrusive caregiving practices (Lyons-Ruth & Block, 1996).

Additionally Bowlby (1973, 1988) argued that the internal model predicts how adults view themselves and other relationships. This idea was advanced by other attachment researchers (see for example, Waters, Merrick, Treboux, Crowell, and Albersheim, 2000, Hazan et al., 1987, and Bartholomew and Horowitz, 1991). There are four adult attachment patterns: secure, anxious-preoccupied, dismissive-avoidant and fearful-avoidant. These adult attachment patterns correspond with the infant attachment patterns namely, secure, insecure-ambivalent, insecure-avoidant and disorganised attachment, respectively (Anand, 2010). Securely attached adults tend to have a sense of self that is likeable and other people as reliable and available. In contrast, anxious-preoccupied adults tend to have a sense of self as unworthy of love and other people as unavailable. Dismissive-avoidant adults often view themselves as self-sufficient and not needing support from other people. Furthermore, they

are uncomfortable with intimacy. Finally, disorganised adults view themselves as unworthy of love. They tend to desire close relationships but simultaneously find it difficult to trust others (Anand, 2010; Chen, Fitzsimons, & Andersen, 2013; Marmarosh & Wellace, 2016).

2.3 Early Studies on Mother-Child Separation

Research on the effects of mother-child separation began in the 1940's with the work of John Bowlby (Senior, 2009). In this section, I will explore early studies by Bowlby as well other influential researchers namely, Spitz and Robertson. Thereafter, I will address the major contributions from Bowlby's early studies as well as some criticisms to his early studies and to attachment theory.

2.3.1 Early studies by Bowlby, Spitz and Robertson. Bowlby observed the long-term effects of separation from their mothers, due to wartime evacuation programmes, on children (Jarvis et al., 2016). In a retrospective comparison between 44 juvenile thieves and a control group of 44 non-criminals, Bowlby (1947) found that more than half of the thieves experienced separations from their mothers for longer than six months during their first five years of life. However, only two participants in the control group experienced mother-child separation (Bowlby, 1947). Additionally, Bowlby (1947) observed that some of the thieves had the personality of what he termed "affectionless characters" – someone who is unaffected by praise or blame (p.20).

Thereafter, the WHO recruited Bowlby to write a report on the effects on children who were left homeless or orphaned after World War II (Bowlby, 1951; Krumwiede, 2001; Shiller, 2017). In this report, Bowlby explored findings from studies that he conducted himself (for example, the study on juvenile thieves), as well as studies performed by other researchers on the effects of deprivation (for example, Spitz 1945, 1946).

Spitz (1945, 1946) compared the effects of children raised in a foundling home to children raised in a nursery attached to a prison in which their mothers were incarcerated. In

the foundling home, children had no contact with their mothers. Furthermore, there was only one nurse caring for several children. In contrast, the mothers and other nurses cared for children in the nursery attached to a prison. Specifically, the mothers paid daily visits to the children in the nursery at the prison. Moreover, in the foundling home, children's cots were covered with a cloth whereas in the nursing home children were able to observe the nurses and other children during the day. After one year, children in the foundling home were withdrawn, showed little interest in their environment, and cried continuously. After three years, children in the foundling home displayed major developmental delays including difficulties walking and speaking. Spitz coined the terms "hospitalism" (Spitz, 1945, p.53) and "anaclitic depression" (Spitz & Wolf, 1946, p.339) to describe the adverse effects of emotional and maternal deprivation. In Bowlby's (1951) WHO report, he concluded that in order for a child to grow up to be psychologically healthy, "the infant and young child should experience a warm, intimate, and continuous relationship with his mother (or permanent mother substitute) in which both find satisfaction and enjoyment" (p. 13).

In order to understand how mother-child separation led to the development of psychological difficulties, Robertson and Bowlby (1952) observed children between the ages of six months and four years who had been separated from their mothers during hospitalisation (Van der Horst, 2011). According to hospital policy, mothers were only allowed to visit their children for one hour per week (Brain & Mukherji, 2005; Karen, 1994). Robertson and Bowlby (1952) observed a recognisable pattern of behavioural and emotional reactions to mother-child separation; namely protest, despair, and detachment. Robertson and Bowlby (1952) noticed that during the first phase (protest) children cried loudly, shook their cots, and appeared hypervigilant of their surroundings. When mothers visited their children during this stage children cried, appeared clingy, or even rejected their mothers. Robertson and Bowlby (1952) identified that this phase lasted between a few hours to one week. They

speculated that the behaviour in this phase indicated that children were distressed and desperate to reunite with their mothers (Van der Horst, 2011).

Additionally, Robertson and Bowlby (1952) noticed that children who remained separated from their mothers entered into a second phase (despair) in which they were quiet and withdrawn. Bowlby (1969) observed that children still cried during this phase, but the crying was more monotonous and less demanding on health workers (Van der Horst, 2011). During this phase, Bowlby (1969) noticed that children continued to reject their mothers during visitation. Furthermore, Robertson and Bowlby (1952) theorised that children in this phase were mourning the loss of their mothers (Van der Horst, 2011).

Lastly, Robertson and Bowlby (1952) suggested that those children who experienced repeated or prolonged separations from their mothers, entered into the final phase of detachment. Robertson and Bowlby (1952) observed that children in this phase were sociable and smiled often (Van der Horst, 2011). However, according to Bowlby (1969) children in this phase, usually appeared apathetic to their mother's presence when she visited. Bowlby (1969) postulated that children coped with the emotional pain associated with their need for comfort from their mother not being met, by detaching emotionally. Bowlby theorised that detachment would lead to later difficulties in establishing close relationships (Barrett, 2005). Based on these early findings, Bowlby formulated attachment theory.

2.3.2 Contributions and limitations. Bowlby's attachment theory has been influential in the formulation of guidelines for childcare practices (Partis, 2000). Additionally, Bowlby's publication of the WHO report and his early findings led to drastic changes in public policy on adoption and hospital practices (Hatfield, 2013; Karen, 1994, 2007; Pilgrim, 2017). Bowlby (1951) convinced policy makers that a mother's care was preferable to separation, with the only exceptions of abuse or neglect. Policy makers

transformed the laws of childcare during hospitalisation to prioritise the mother-child relationship (Shields & Mohay, 2001).

However, the success of attachment theory has not been without criticism. Many researchers argued against Bowlby's theory that disruptions in the mother-child relationship caused psychological problems. These theorists attributed the behavioural and emotional problems in children to other variables, such as the child being in a strange environment (Bowlby, 1969). Bowlby (1969) responded to these criticisms by reviewing the literature on children hospitalised with the on-going presence of their mother and children separated from their mothers whilst in their home setting. For example, Robertson (1958) observed that children who were hospitalised with their mother were secure and not withdrawn despite being in a strange environment. Additionally, Spiro (1958) explored how a child responded to a separation from his mother whilst being cared for by a familiar nurse in his home setting. The child displayed behaviour of withdrawal and mourning. When the child's mother returned, the child rejected her and appeared to forget who she was. Therefore, Bowlby (1969) argued that the strange environment is not the source of the child's psychological problems but rather mother-child separation caused children to develop behavioural and emotional problems.

Another criticism of Bowlby's work was that he used a retrospective research design that limited the extent to which he could establish cause-and-effect conclusions. Bowlby was not able to account for children who experienced separation from their mother but did not commit crimes (Crozier, 1997; Yarrow, 1964). However, other researchers, such as Ainsworth and Waters, responded to this limitation by conducting prospective studies which yielded similar conclusions to Bowlby's retrospective study (see for example, Ainsworth, 1967; Ainsworth et al., 1978; and Waters et al., 2000).

Additionally Bowlby has been criticised for focusing on the mother-child relationship whilst neglecting the role of other family relationships (for example, the mother's partner, grandparents, and siblings), peer relationships, and other institutions (the child's school; Thompson, 2005). Social network analysts argue that the mother-child relationship is not the only relationship that helps children to develop security (Thompson, 2005). However, Bowlby (1951) explained that the role of the mother could be replaced with a "permanent mother substitute" (p.13). Furthermore, Spitz (1949) specified that the term 'mother' refers to the biological mother and/or any person of either sex who is the substitute of the mother for a significant period of time[1]. Contemporary attachment theory does recognise the role of other caregiver-child relationships on children's development; including for example, the mother's partner, fathers, grandmothers, and nannies (Bretherton, 2010; Jaffee, Van Hulle, & Rodgers, 2011; Music, 2017). Studies that explore the effects of non-maternal care on children's development are addressed in more detail in the following section.

There are also criticisms of attachment theory with regard to its applicability cross-culturally. There are specific characteristics of many African cultures that challenge the assumptions of attachment theory. For example, it is a common practice in many African contexts, including South Africa, for multiple caregivers to raise an infant (Hrdy, 1999). Nontheless, attachment theory's assumption of monotropy holds that an infant's relationship to a single caregiver forms the foundation of the infant's socio-emotional development (Bowlby, 1951).

However, Bowlby and other attachment theorists argue that attachment behaviours are universal. In a study conducted in Uganda, in which multiple caregiving is a popular practice, children displayed a differential attachment to their primary caregiver alongside multiple attachments to other caregivers (Bowlby, 1969). Bowlby (1969) used this evidence to argue

[1] From now on, I use the word caregiver to refer to the person who serves as the primary caregiver of the child.

that children do attach to a primary caregiver and that attachment behaviours are evident in a variety of cultural contexts. In spite of these criticisms, Bowlby and Robertson's work is considered to have laid the crucial foundations for what we know about caregiver-child separation today (Bretherton, 1992).

2.4 Non-Maternal Care

Researchers do not have consensus as to whether non-maternal care (for example, childcare by grandmothers and nannies or childcare in day-cares, orphanages, and hospitals) is harmful to children (Jaffee et al., 2011; Music, 2017). Some studies indicated that children who experienced non-maternal care before they turned one, were more likely to be aggressive (Bates et al., 1994; NICHD Early Child Care Research Network, 2003). However, other studies showed that the earlier a child experienced non-maternal care and the more time the child spent in non-maternal care, the higher the child scored on positive socio-emotional and cognitive measures (Andersson, 1992; Field, Masi, Goldstein, Perry, & Parl, 1988).

Researchers have explored whether the differences in the findings were because of the variety of types of non-maternal care. Children can experience non-maternal care in the context of one-on-one care (for example, care by nannies or grandmothers) or in a group setting (for example, day-cares, orphanages, and hospitals; Music, 2017). Caregivers had fewer instances of emotional responsiveness in a group setting than caregivers in one-on-one care (Leach, 2009). Moreover, children were less likely to have a secure attachment pattern when cared for in a group setting, than when cared for by one caregiver at home (Ahnert, Pinquart, & Lamb, 2006; Leach, 2009). Given that in a group setting caregivers need to focus on the needs of the group rather than the needs of the individual child (Music, 2017), these findings can be expected. Caregivers in a group setting are often unable to help infants manage their distress (Music, 2017). Therefore, in a group setting, caregivers are rarely able to fulfil the role of a substitute primary caregiver (Music, 2017). Although the research is

inconclusive about whether non-maternal care is harmful for children, it is clear that one-on-one non-maternal care provides children with more emotional support than non-maternal care in a group setting (Leach, 2009).

2.5 Children's Responses to Caregiver-Child Separation

In this section, I explore children's responses to caregiver-child separation in the context of a group-care setting such as an institution, a day-care, or a hospital. Caregiver-child separation can also be classified into two other categories; namely privation and deprivation (Jarvis & Chandler, 2001). Privation can happen when separation occurs prior to attachment formation. As a result, the child is unlikely to form an attachment relationship to his/her caregiver (Rutter, 1998). Deprivation refers to a child's experience of losing or damaging his/her attachment relationship. This can occur when separation happens after the formation of an attachment relationship (Rutter, 1998). I begin by exploring research on children's behavioural and emotional responses to privation. Thereafter, I consider research studies on short-term deprivation, as seen in day-care and brief hospitalisation; and then long-term deprivation, as seen in long-term hospitalisation.

2.5.1 Privation. Privation can occur in the context of institutional care (Jarvis & Russell, 2008). Children who experienced institutionalisation developed long-term behavioural problems (Hodges & Tizard, 1989; Rutter, 1998). Nonetheless, some of the behavioural problems were reversible with good quality care from an early age. For example, orphans who initially displayed developmental delays caught up with the expected developmental milestones after four years in foster homes (Rutter, 1998). Consequently, children who were adopted displayed fewer behavioural problems than children who remained in institutional care (Hodges & Tizard, 1989). However, some behavioural problems such as clinginess, attention seeking, and indiscriminate sociability seemed to

remain despite good quality care. Rutter called these behaviours “disinhibited attachment” (Rutter et al., 2007, p. 1200).

2.5.2 Deprivation: Short-term separation. Children can experience short-term separation when attending a day-care or during a hospital admission for less than a week.

2.5.2.1 Day-care. Music (2017) reported that children experienced distress when attending a day-care. Toddlers experienced 75% to 100% higher levels of the stress hormone, cortisol, for the first two weeks that they were attending a day-care without the presence of their primary caregiver, as opposed to when they were at home. Furthermore, cortisol levels were still significantly higher than home baseline levels five months after the child started attending day-care (Ahnert, Gunnar, Lamb, & Barthel, 2004).

Many factors influenced the outcome of day-care attendance on children’s development (Music, 2017). Firstly, the better the quality of the day-care, the better the behaviour and emotional outcomes were for children (Music, 2017). Factors which had a positive influence on day-care quality included: good ratios between caregivers and children, continuity of caregivers, and emotionally responsive caregivers (Music, 2017). Additionally, temperament, age, and the family background of the child influenced the outcome of day-care on children. Children with higher negative affectivity depicted higher stress levels than their peers when attending day-care (Dettling, Parker, Lane, Sebanc, & Gunnar, 2000). Moreover, children aged three years and under displayed higher cortisol levels than older children when attending day-care (Dettling, Gunnar, & Donzella, 1999; Ouellet-Morin et al., 2010).

The ‘dual-risk’ of unresponsive caregivers at home, coupled with unresponsive caregivers at a day-care led to more severe, negative effects of day-care on children’s development (Huston, Bobbitt, & Bentley, 2015). Since children who had a troubled family background, and who attended poor-quality day-care, would likely receive unresponsive caregiving both at home and at day-care, such children were at greater risk of developing

long-term problems (Music, 2017). Conversely, children who had a difficult family background developed new social and coping skills (for example, emotional regulation, and academic skills) from attending a good quality day-care (Berry et al., 2016; Finch, Johnson, & Phillips, 2015; Melhuish, 2004).

Overall, the literature indicates that attending day-care was stressful for children. However, positive factors (for example, a good quality day-care) buffered these negative outputs; whereas negative factors (for example, entering day-care prematurely) exacerbated the problematic effects of day-care on children.

2.5.2.2 Brief hospitalisation. Short-term separation as seen in brief hospitalisation, led to short-term difficulties but not to significant long-term problems (Quinton & Rutter, 1976). Children hospitalised once without their caregiver, for an average of one week, and before the age of five had symptoms of depression and anxiety, despite their caregivers visiting regularly (Quinton & Rutter, 1976). Presumably, these children developed psychological problems because of caregiver-child separation and/or from other hospital-related factors such as, injections, blood tests or operations (Boyd & Hunsberger, 1998; Eysenck, 2005). However, these children did not have persisting symptoms by the age of ten (Quinton & Rutter, 1976).

Additionally, children had fewer behavioural problems when they had the support of a substitute mother during hospitalisation. Children, aged between two to three years, who were hospitalised for one week were compared across three conditions of separation:

i. the mother-present group: the mother remained with the child during hospitalisation;
ii. the substitute-mother group: the mother did not stay in the hospital but a substitute mother cared for the child during working hours; and

iii. the mother-absent group: the mother did not stay in the hospital and the child did not have a substitute mother.

Children in the mother-absent group showed the most significant distress with behaviours such as anger, crying, and withdrawal (Branstetter, 1969). In comparison with the children in the mother-absent group, the children in the mother-present group and in the substitute-mother group cried and withdrew less and interacted more with others. The children in the substitute-mother group initially did not engage willingly with the substitute mother but after a few days, children initiated contact with the substitute mother. However, the substitute mother did not replace the child's relationship with his or her mother. When the mother visited or collected her child, the child reached towards his or her mother despite the presence of a substitute mother (Branstetter, 1969).

Overall, brief hospitalisation, led to short-term difficulties but not to significant long-term problems. Additionally, children had fewer behavioural problems when they had the support of a substitute mother. However, this support was not as beneficial as the presence of a mother.

2.5.3 Deprivation: Long-term separation. Long-term caregiver-child separation, regardless of the reason for separation, often caused psychological problems for children. Caregiver-child separation, due to a caregiver's holiday, business travel, or illness, for one week or more before the age of two years, was linked with child negativity at three years and childhood aggression at three and five years (Howard, Martin, Berlin, & Brooks-Gunn, 2011). Additionally, caregiver-child separation (for similar reasons: a caregiver's holiday, business travel or illness), for more than a month before the age of five was associated with the development of borderline personality disorder symptoms in adolescence and adulthood (Crawford, Cohen, Chen, Anglin, & Ehrensaft, 2009).

2.5.3.1 Long-term hospitalisation. In a review of the literature, presented by Bonn (1994) and Melnyk (2000), children's responses to caregiver-child separation during long-term hospitalisation included: behavioural regression, sleep disturbance, depression, apathy, aggression, hyperactivity, as well as anxiety. As mentioned previous, in addition to caregiver-child separation, other stressors during hospitalisation could have also contributed to the development of these problems (Boyd & Hunsberger, 1998; Eysenck, 2005; Melnyk, 2000). Melnyk (2000) and Bonn (1994) cited studies dating from the 1950s to 1990s. Recently, the psychological impact of long-term hospitalisation has received little research attention.

Most problems subsided after a few months post-hospitalisation but prolonged or repeated hospitalisations increased the chances of the long-term effects of hospitalisation. In a study by Prugh, Staub, Sands, Kirschbaum, and Lenihan (1953), 92% of children had behavioural and emotional problems immediately after discharge. However, three months post hospitalisation, only 58% of children had behavioural and emotional problems. Additionally, three months after hospitalisation, the degree of severity of the symptoms was milder than immediately after discharge. However, in other studies by Douglas (1975) as well as Quinton and Rutter (1976), frequent hospitalisation with at least one admission lasting between six months and five years was associated with a psychiatric disorder and delinquency in adolescence.

Factors associated with the development of behavioural and emotional problems in children in the context of caregiver-child separation during long-term hospitalisation were: duration of separation (Douglas, 1975; Vernon, Schulman, & Foley, 1966) and the age of the child (Vernon et al., 1966). Overall, longer-term hospital stays (Douglas, 1975; Vernon, Schulman, & Foley, 1966) and hospital stays among younger children (children aged between six months and four years; Vernon et al., 1966) were more likely to lead to long-term problems.

In contrast, children experienced lower levels of distress during hospitalisation when their caregivers visited them daily and even less distress when their caregivers stayed with them in hospital (Brian & Maclay, 1968; Hawthorne, 1974; Illingworth & Holt, 1955). Children with previous experience of being separated from their parents (for example when staying over at grandparents or friends) were less likely to experience distress during hospitalisation or aggression post-hospitalisation (Stacey, Dearden, Pill, & Robinson, 1970; Youngblut & Brooten, 1999). Psychological preparation for hospitalisation, including pre-hospitalisation tours, books about hospitalisation, and films modelling the hospital experience decreased the negative outcomes of hospitalisation (Ferguson, 1979; Melamed & Seigel, 1975; Vernon et al., 1966; Visintainer & Wolfer, 1975).

Therefore, according to existing literature, long-term separation regardless of the reason for separation, contributed to the development of behavioural and emotional problems in children. However, there were factors, such as parents staying with their children during hospitalisation and psychological preparation for hospitalisation, which decreased the negative effects of caregiver-child separation during long-term hospitalisation. On the other hand, if separations during hospitalisation were prolonged or repeated, children were more likely to develop long-lasting problems.

2.6 Perceptions of Caregiver-child Separation and Long-term Hospitalisation

In this section, I explore caregivers' and health workers' perceptions of the effects of caregiver-child separation during long-term hospitalisation on both themselves and on the children. Firstly, I address the challenges that caregivers encountered when their children were hospitalised long-term. Thereafter, I explore the challenges that health workers experienced when caring for children who had been separated from their caregivers during long-term hospitalisation. Finally, I describe the ways in which caregivers and health workers typically interpreted children's responses to separation during long-term hospitalisation.

2.6.1 Challenges experienced by caregivers and health workers. Caregivers described feeling a sense of anxiety and guilt when their children were in hospital long-term. Caregivers cited caregiver-child separation (Alexander, 1988; Loveday et al., 2018) and a lack of information regarding their children's illnesses (Freinberg, 1972; Skipper, Leonard, & Rhymes, 1968) as major sources of anxiety. Additionally, caregivers felt anxious and stressed when their children ignored and rejected them during hospital visits (Freinberg, 1972; Glaser, 1960; Melnyk, Small, & Carno, 2004). Moreover, caregivers felt guilty for being the source case (Loveday et al., 2018) and for failing to prevent their children from contracting the illness (Freinberg, 1972; Tiltman, 1984).

Health workers also felt anxious and guilty when caring for children who were hospitalised long-term. Health workers reported feeling anxious about forming close relationships with the children in hospital in anticipation of (i) the loss they might feel when children are discharged; (ii) children becoming too dependent on them; and (iii) children's caregivers resenting them (Elfer & Page, 2015; Music, 2017). Health workers felt guilty for hurting children during medical procedures (Livesley, 2005). In addition, health workers reported that it was a challenge to provide emotional support and to be a parental substitute for children (Freinberg, 1972; Livesley, 2005). Both caregivers and health workers experienced challenges resulting from caregiver-child separation during long-term hospitalisation.

2.6.2 Interpretations of children's responses to hospitalisation. According to Bowlby and Robertson, health workers and caregivers previously misinterpreted children's behavioural and emotional responses to caregiver-child separation based on their understanding of childhood at the time (Leifer, 2015; Sanders, 2014; Smith & Ford, 2008). As a result, children who were separated from their caregivers during hospitalisation were often left with unmet needs (Sanders, 2014). In the following section, I explore caregivers'

and health workers' misinterpretations of children's responses to caregiver-child separation during the phases of: (i) protest, (ii) despair, and (iii) detachment (Van der Horst, 2011).

Robertson and Bowlby (1952) explained that during the protest phase, children cried because they were distressed (Van der Horst, 2011). Nonetheless, health workers previously labelled crying in the protest phase as bad behaviour (Leifer, 2015; Sanders, 2014). During this phase, children cried more when their caregiver arrived or left from a visit. As a result, health workers and caregivers assumed that the visit disturbed children's adjustment to the hospital (Sanders, 2014; Tiltman, 1984). Consequently, caregivers decided to visit their children less and health workers restricted visitation from parents (Sanders, 2014; Tiltman, 1984). In addition, during the protest phase, children often displayed stranger-anxiety by crying when a health worker approached them. Previously, health workers did not understand the cause of children's behaviour to be fear and anxiety. As a result, health workers withdrew from the children as opposed to providing them with comfort (Sanders, 2014).

In the second and third phases, health workers assumed that children's lack of crying was an indication that they were settling in to the hospital (Leifer, 2015; Sanders, 2014; Tiltman, 1984). However, according to Bowlby (1969), withdrawal and detachment were other ways in which children in hospital communicated distress at being separated from their caregivers. Specifically, in the second phase (despair), children cried less because they had transitioned from protesting for their caregiver's return to mourning the loss of their caregiver. In the final stage (detachment), children cried less because they were detaching emotionally to prevent the pain associated with their needs for their caregiver not being met. Therefore, many health workers and caregivers misinterpreted children's responses to separation, based on their understanding of childhood at the time (Leifer, 2015; Sanders, 2014; Smith & Ford, 2008).

2.7 Caregiver-child Separation during Long-term Hospitalisation for MDR-TB in South Africa

The psychosocial impact of MDR-TB treatment on children, their caregivers and health workers, in the South African context, is poorly understood (Franck et al., 2014; Hoddinott & Hesseling, 2018). Nonetheless, Franck and colleagues (2014) as well as Loveday and colleagues (2018) made initial progress in trying to understand the psychological impact of MDR-TB treatment in the Western Cape and KwaZulu-Natal, respectively.

They highlighted that during MDR-TB treatment, children developed behavioural, emotional and cognitive difficulties including: drowsiness, decreased intellectual functioning and in extreme cases, psychiatric disorders. Additionally, they listed potential factors that might have contributed to the development of these difficulties including: being ill with MDR-TB, MDR-TB treatment, the adverse effects of the medication, anxiety about being stigmatized, the unpalatable nature of pills, the financial burden of disease, missing school and losing a parent to MDR-TB or HIV (Franck et al., 2014; Loveday et al., 2018). Furthermore, Loveday and colleagues (2018) explained that caregiver-child separation during long-term hospitalisation might have contributed to children's development of behavioural and emotional problems.

However, Franck and colleagues (2014) did not address caregiver-child separation in the context of long-term hospitalisation. Therefore, to the best of my knowledge, there is no literature in the Western Cape that explores caregiver-child separation during long-term hospitalisation for MDR-TB.

2.8 Conclusion

Caregiver-child separation, irrespective of the context (institution, hospital, or day-care), contributed to the development of psychological problems in children. However,

factors such as the time at which caregiver-child separation occurred; the duration of caregiver-child separation; and the presence of other variables (for example, the child's age or temperament) moderated the effects of caregiver-child separation on children's development. Therefore, children who are separated from their caregivers due to long-term hospitalisation are at risk of developing long-term behavioural and emotional problems. However, it is unclear whether these theories are still relevant and apply to the context of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.

Chapter 3: Methods

3.1 Introduction

In this chapter, I explain how I conducted the study. Firstly, I describe the research design, setting, and sample. Thereafter, I clarify how I collected and analysed the data. I end this chapter with a description of the ethical procedures and considerations.

3.2 Research Design

I used a qualitative research design. The research design influences the (i) research paradigm, (ii) research method, and (iii) the form of data (Braun & Clarke, 2013). I adopted a non-positivist qualitative paradigm. According to this paradigm, reality is not singular but rather there are multiple realities shaped by an individual's unique context (Braun & Clarke, 2013). Additionally, I adopted a qualitative research method. This involved interviewing participants to formulate a rich description and deep understanding of their experiences (Braun & Clarke, 2013; Hartmann, Abbott, & Pelzel, 2015; Willig, 2013). Finally, I used non-numerical data – data that is in the form of words that are not reducible to numbers (Braun & Clarke, 2013). A qualitative research design was appropriate for this project as I aimed to describe caregivers' and health workers' perceptions of caregiver-child separation.

3.3 Research Setting

The study took place in the Western Cape, South Africa, a province with one of the highest MDR-TB burdens worldwide (WHO, 2013). In 2012, there were 47 849 cases of TB in the Western Cape. Of these cases, 4 877 (10%) were children aged zero to five years (Garcia-Prats, 2016). Additionally, between 2011 and 2013, 4.7% of children with active TB disease at TCH had MDR-TB (Schaaf, Garcia-Prats, Preez, Rautenbach, & Hesseling, 2016).

In the Western Cape, 50% of paediatric TB patients are black and fifty percent are coloured[2] (Garcia-Prats, 2016).

Interviews were conducted at TCH and BCH. In the Western Cape, some children with MDR-TB receive community-based care with regular follow-up appointments at TCH; whilst others are admitted to BCH for the initial part of treatment (six months of daily injections). Thereafter, the children discharged from BCH receive community-based care with regular follow-ups at TCH (Franck et al., 2014; Seddon et al., 2014; WHO, 2008).

3.4 The Larger Project

MDR-PK II is a longitudinal, observational, and pharmacokinetic study of children (aged zero to seventeen years) who are receiving routine treatment for DR-TB with key second-line TB drugs. The study is implemented by the Desmond Tutu TB Centre (DTTC) in the Department of Paediatrics, Stellenbosch University (Garcia-Prats, 2016). MDR-PK II aims to establish the best dosage of three of the most important medications for MDR-TB and to check whether these dosages are safe and palatable for children with MDR-TB (Garcia-Prats, 2016). MDR-PK II research staff approach all children presenting at the regional TB referral hospitals and referring community clinics for routine DR-TB treatments in an attempt to recruit all children in the Western Cape who have MDR-TB (Garcia-Prats, 2016). My study was an ancillary study to MDR-PK II and addressed the third objective of MDR-PK II: to characterise the acceptability of DR-TB treatment (Garcia-Prats, 2016).

3.5 Participants

3.5.1 Outline of the intended sample. Initially, I set out to interview caregivers and health workers of children who were receiving routine treatment for DR-TB as part of the larger MDR-PK II study (Garcia-Prats, 2016). Specifically, I was interested in the children

[2] The term ‘coloured’ is rooted in apartheid’s racial classification system and continues to persist in contemporary South Africa.

who were in hospital at BCH at the time of the interview or who had been discharged from BCH and were receiving outpatient care at TCH. I wanted to interview caregivers and health workers of children aged zero to five years. I chose this age range because Bowlby (1944) argued that a disruption in the attachment bond between an infant and their caregiver, before the age of five years, could result in long-term emotional and social difficulties (Van der Horst, 2011). Additionally, previous studies indicated that the younger the child, the more likely the child is to experience poor outcomes associated with long-term hospitalisation (Douglas, 1975; Rutter, 1987; Vernon et al., 1966). Furthermore, children under the age of five are at higher risk of TB acquisition (Department of Health Republic of South Africa, 2015) because they do not have a fully developed immune system (WHO, 2016). However, I did not want to include the children themselves as participants in the sample because children under the age of five typically have difficulty verbally expressing rich answers to complex questions (Crawford & Brown, 2009).

I chose caregivers as well as health workers to facilitate triangulation. Triangulation involves analysing the research question from multiple perspectives, thus increasing the credibility of the data (Roberts-Holmes, 2005). I wanted to recruit an equal number of black and coloured caregivers to match the distribution of the population of children living with TB in the Western Cape (Garcia-Prats, 2016). I set out to interview some health workers who worked for the MDR-PK II study and some health workers who worked at the paediatric ward at BCH (but who were not affiliated to the research study).

3.5.2 Sample size. I aimed to recruit approximately 20 participants. The sample size was chosen based on sample sizes from similar studies; namely Franck and colleagues (2014) and Loveday and colleaguess (2018) who selected between twenty to thirty participants. Ultimately, the sample size was determined by data saturation. Saturation means that the data

is robust and there are no unexplained phenomena preventing the researcher from answering the research question (Given, 2008).

3.5.3 Sampling strategies. The MDR-PK II research counsellors approached all caregivers of child MDR-PK II participants who were hospitalised at BCH during the period of data collection (April 2018 to August 2018). Since MDR-PK II aims to recruit all children with MDR-TB in the Western Cape and my study is a sub-study of MDR-PK II, we tried to reach all caregivers of children who were hospitalised for MDR-TB in the Western Cape between April 2018 and August 2018.

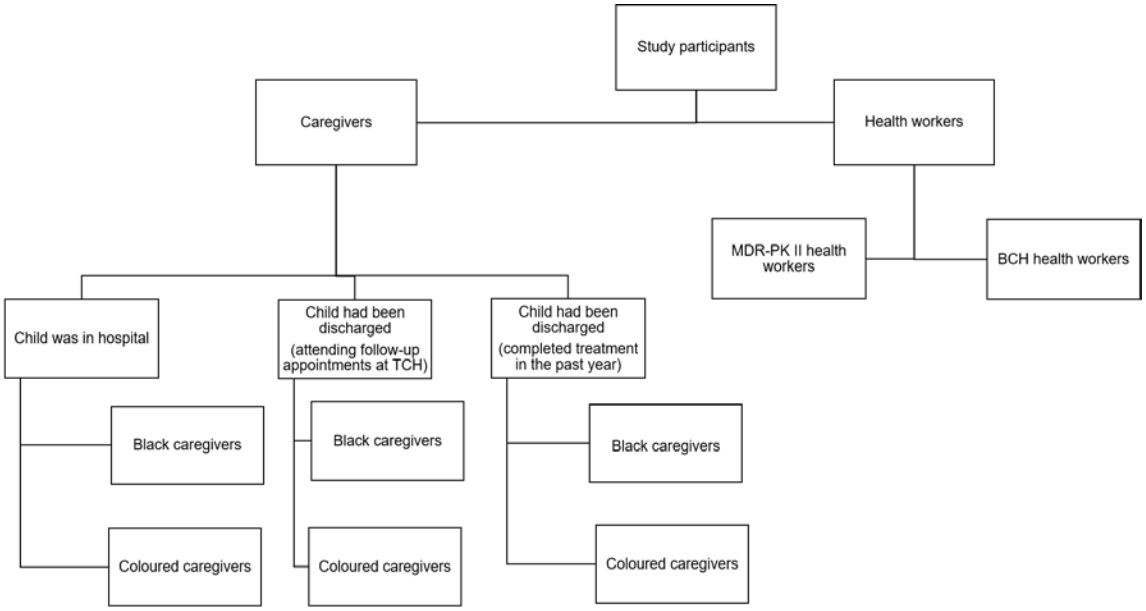
To recruit the health workers and caregivers of children who had been discharged from hospital, we used convenience sampling. Convenience sampling involves selecting participants because they are easily accessible, available at a certain time, and willing to participate (Bless & Higson-Smith, 2000; Dörnyei, 2007). Convenience sampling is a type of non-probability sampling technique. In non-probability sampling techniques, not all individuals in the population are given an equal chance of being selected into the sample. Rather, subjective measures are used to decide which participants are selected from the population to be a part of the sample (Etikan, Musa, & Alkassim, 2016).

The MDR-PK II research counsellors recruited caregivers of children who were attending follow-up appointments at TCH during the period of data collection. After the list of these participants was exhausted, MDR-PK II research counsellors recruited caregivers of children who had completed treatment in the past year and who answered their phones. We only recruited two black caregivers on this list since the remaining black caregivers on the list did not answer their phones. The research counsellors suspected that they could not get hold of many of these caregivers because they had changed their contact numbers. We did not recruit all coloured caregivers on this list because we reached saturation at ten coloured caregivers. We recruited health workers who were at work on the days that we conducted

data collection and who were willing to participate in the study (see Figure 1 for a summary of the composition of participants).

Figure 1

Composition of Participants



3.6 Preparation for Data Collection

This section provides an overview of the preparation for data collection procedures including informed consent and constructing the tools for data collection.

3.6.1 Information sheet and consent form. I formulated the information sheet and consent form (See Appendix A) based on a sample consent form used at the DTTC. The Health Review Ethics Committee of Stellenbosch University, the principal investigator of MDR-PK II, and my supervisors reviewed the consent form before I finalised the document by incorporating their comments.

3.6.2 Discussion guide. I formulated the discussion guide with input and guidance from my supervisors and colleagues. The discussion guide (See Appendix B) covered a broad range of topics including: (i) background information of the child and their family; (ii) the

child's relationship to their caregiver(s); and (iii) the child's experiences of caregiver-child separation during hospitalisation.

3.6.3 Translation. Since English, Afrikaans and isiXhosa are the three dominant languages in the Western Cape (Western Cape Language Committee, 2002), I offered participants the option to have their interview in English, Afrikaans or isiXhosa. isi-Xhosa-speaking and Afrikaans-speaking research assistants working at DTTC translated the consent form and the discussion guide from English into isiXhosa and Afrikaans. The translated versions of the consent forms and discussion guides are available upon request. Subsequently, I met with other isi-Xhosa-speaking and Afrikaans-speaking research assistants, who were assisting with data collection, to check the translations. I read and explained each question of the discussion guide to the research assistants in English. The research assistants then described the wording of the questions in the isiXhosa and Afrikaans versions. We discussed whether the translations required any changes. Thereafter, they edited all versions accordingly.

3.6.4 Training. The research assistants, who assisted with data collection and processing, and I received training in ethical principles and research skills (interviewing techniques as well as transcription and translation skills) through the DTTC. Additionally, before data collection began, we role-played the discussion guide with some of our colleagues at the DTTC to familiarise ourselves with the discussion guide.

3.6.5 Recruitment. I introduced the project to senior MDR-PK II research nurses and counsellors based at BCH and TCH. I asked these health workers whether they wanted to participate in my study and I asked them to assist me with identifying other potential participants. They contacted caregivers that matched my selection criteria and asked them whether they wanted to participate in the study. Thereafter, the research counsellors organised meetings with the potential participants, the interviewers and me at a time suitable

for all of us. During the meeting, I reintroduced the study to the caregivers and confirmed whether or not they wanted to participate in the study.

The senior MDR-PK II research nurses also introduced me to other MDR-PK II health workers that matched my selection criteria. I approached these health workers, explained the study and asked them whether or not they wanted to participate.

I then introduced the project to a senior nurse at the paediatric ward at BCH. I asked her whether she would like to participate in the study. Additionally, I asked her to assist me with identifying health workers who worked directly for BCH and who matched my selection criteria. I approached the potential health workers, explained the study to them and asked them whether or not they were interested in participating in the study. Finally, when a caregiver or health worker agreed to participate in the study, I organised an interview on a date and time that was suitable for the interviewers, the participants and me.

3.6.6 Informed consent. At the start of each interview, the interviewer presented a copy of the information sheet and informed consent document to the participant. The informed consent procedure addressed the following ethical consideration procedures: confidentiality and anonymity, the benefit and risk of participation in the study, reimbursement, and referral for counselling. The interviewer explained the consent form to the participant. If the participant agreed to participate in the study, the participant signed two copies of the consent form – one copy for the researcher and one copy for the participant to keep. None of the potential participants were unable to read and sign the consent forms. As such, although I made provision for witnessing and thumbprints, this was unnecessary.

3.7 Data Collection and Data Analysis

Data analysis ran parallel to data collection. In an iterative process, I conducted the initials interviews, analysed these interviews, and thereafter continued with further data collection and analysis. This iterative data collection and analysis process was informed by

Glaser and Strauss' (1967) constant comparison approach to data collection and analysis. By using this iterative process to data collection and analysis, I was able to adjust the discussion for the second round of data collection based on the findings from the preliminary analysis (See Appendix C and D).

3.7.1 Data collection procedures. The research assistants and I used semi-structured, in-depth interviews as the method of data collection. During semi-structured interviews, the researcher uses a discussion guide, with predetermined, open-ended questions, to guide the interview (Miles & Gilbert, 2005). Additionally, the interviewers and I used probes where further exploration about the participants' responses were required and active listening to build rapport with the participant (Lioness, 2008). The in-depth nature of the interviews enabled me to unpack and explore the participants' perceptions (Ritchie & Ormston, 2014).

The interviews were conducted in one of the following venues: (a) a doctor's room at the Paediatric Clinic at TCH; (b) in a prefabricated room at the DTTC's Research Unit based at BCH; or (c) in a private room at the Paediatric Ward at BCH. Data collection took place between April 2018 and August 2018. Most of the interviews were individual – with the mother of the child, the father of the child or the health worker – but in two instances, the interviews were with both the mother and the father. Each interview took between 45 and 90 minutes to complete.

After the participants signed the consent form, I turned on the voice recorder and the interviewer read the preamble to the interview. We conducted the interviews in the participants' chosen language. I conducted interviews with English-speaking participants and I co-facilitated the interviews with an Afrikaans- or isiXhosa-speaking research assistant where this was the participants' preference.

Furthermore, after each interview, I de-briefed with the research assistant who conducted the interview and wrote reflective notes about the interview. We discussed how

their social position (gender, race, and social class) as well as their assumptions about the world may have influenced the way in which they formulated some of the questions and thus how the participants' responded to the questions (Given, 2008; Macfarlane, 2016). We also reflected on notable observations during the interview.

For example, the Afrikaans-speaking research assistant reflected that some people who speak *Kaapse* Afrikaans might feel inferior to her if she addressed them in standard Afrikaans dialect during the interview. In the development of Afrikaans in South Africa, one dialect was enforced as official by the white minority. This dialect was positioned as more pure and was instrumental in the maintenance of apartheid social manipulation. In contrast, many coloured Afrikaans-speakers use a dialect colloquially known as *Kaapse* Afrikaans. While the language structure is coherent between the two dialects, the diction is markedly different and there are some dialect-specific words (Cooper, 2016). In our reflection meeting, the Afrikaans-speaking research assistant said that she often started the interview by explaining that the preamble was in formal Afrikaans "from the university" and the participants should not laugh at her reading of it. We discussed that this remark was an attempt to distance herself from standard Afrikaans in order to show the participants that she could relate to them in *Kaapse* Afrikaans. The research assistants and I reflected on how this might have made the participants more comfortable to speak openly to the research assistant.

3.7.1.1 First round of data collection. In the first round of data collection, we conducted five interviews. I then paused data collection and began the analysis (I discuss the process of data analysis in section 3.7.2 on 'Data analysis procedures').

3.7.1.2 Second round of data collection. I met with the research assistants to explain the changes to the discussion guide (discussed in section 3.7.2.3 on 'Preliminary analysis'). Thereafter, we continued with data collection. I terminated data collection when I reached saturation at 19 interviews. I felt confident that I had reached data saturation when the

interviews became repetitive and participants no longer relayed novel information (Evans, 2007). For the interviews that were conducted in English, I was able to observe whether I had reached saturation during data collection. However, for the interviews that were in isiXhosa or Afrikaans, I de-briefed with the interviewers after each interview in order to assess whether we were reaching saturation. Nonetheless, I was only able to confirm that we had reached saturation once I had read all the transcripts, after the research assistants transcribed and translated them.

3.7.2 Data analysis procedures. As mentioned previously, I conducted a preliminary analysis on the first five interviews. The findings of the preliminary analysis informed the second round of data collection and analysis. Thereafter, I conducted a full analysis of all 19 transcripts.

3.7.2.1 Transcription procedures. Transcription was conducted according to the DTTC Transcription Protocol (See Appendix E for an extract from the protocol). I used codes to represent the participants' identities by sequentially numbering the interview. In the code, I also indicated the language in which the interview was conducted as well as whether the participant was a caregiver or health worker, woman or man and coloured or black. For example, I coded participant one as: I1_A_Ca_W_Co[3].

Thereafter, the researcher assistants and I transcribed the original audio recordings verbatim. We also used symbols to indicate laughter, pause, latching, interruption, pitch, pace, and breathe. Additionally, the transcriber included additional explanations about the interviews that were not easily explainable with symbols in double brackets. An example of this is: ((participant giggles nervously)). See Appendix F for an extract from a transcript. I

[3] Key for participant code:
I1-I19: The interview number; A:Afrikaans; X:isiXhosa; E: English; Ca: Caregiver; HW: Health worker; W: Woman; M: Man; Co: Coloured; B: Black

used these details while I was conducting the analysis. However, I did not present extracts in Chapter 4 with this level of detail because it made it difficult to read the quotes fluently.

The research assistants then translated all interviews that were in Afrikaans or isiXhosa into English. When there were words in the recording that the researcher could not translate directly into English, the researcher explained the intricacies of the word in double brackets. For example “klouerig” ((“klou” translates directly as claw but in this context the word means to attach/to cling))”. Transcription and translation were conducted in Microsoft Word. Thereafter, I loaded the translated version into ATLAS.ti, a software programme for organising qualitative data, for analysis (Friese, 2014).

3.7.2.2 Thematic analysis. I used thematic analysis as a means to organise and interpret the data. Thematic analysis is a method of recognising, analysing, and reporting patterns within the data (Braun & Clarke, 2006). Thematic analysis was appropriate for the current study because it allowed me to organise the caregivers’ and health workers’ perceptions into meaningful themes that helped me to answer the research question.

In order to conduct the thematic analysis, I followed Braun and Clarke’s six phases of coding and theme development. I also used features on ATLAS.ti. such as coding, linking codes, and grouping codes to assist with my analysis. These tools are known to increase the methodological rigour and sophistication of the analysis (Friese, 2014; Ignatow & Mihalcea, 2016). I will now discuss how I followed the six stages of thematic analysis. Although the six stages are presented in a linear order, the analytic process is in reality an iterative process whereby there is an ongoing moving backwards and forwards between the phases (Nowell, Norris, White, & Moules, 2017).

3.7.2.2.1 Familiarising myself with the data. While I was collecting and transcribing the data, I actively engaged with the data. This involved reading and re-reading the transcripts and noting down any initial ideas. After conducting each interview, I made notes about parts

of the interview that were relevant to my research question and I reported any strong emotions that I felt during the interview. Thereafter, while transcribing the English interviews, I recorded any quotes and ideas that seemed important in relation to the research question. Thereafter, I read each translated transcription at least twice and made further notes about any parts of the interviews that I found particularly interesting or relevant to the research question. I also began to record any emerging patterns or underlying key messages across the data set.

3.7.2.2.2 Generating initial codes. I created codes using inductive coding. This means that the data informed the code formation and the data was the foundation for identifying meaning and interpreting the data (Braun & Clarke, 2006; Terry, Hayfield, Clarke, & Braun, 2017). I attempted to code the data without categorising it into a pre-exiting framework informed by a theoretical approach. However, since I do not exist in an "epistemological vacuum" (Braun & Clarke, 2006, p.12), I did not code the data without pre-conceived ideas about caregiver-child separation during long-term hospitalisation. An example of an assumption that I hold, which might have influenced how I coded the data, is the claim that children require sensitive and responsive caregiving in order to become psychologically healthy.

I created the codes manually on ATLAS.ti. by selecting, tagging, and labelling segments of the text with key statements that summarised that element of the conversation. During the stage of initial coding, I met with my supervisors to discuss my strategies for coding. After the initial round of coding, I read each code and the corresponding segment of data. I re-named some of the codes, merged some codes together, and separated some codes into distinct codes. Thereafter, I compiled a conclusive list of the different codes and their corresponding segments of data.

3.7.2.2.3 Searching for themes. I interpreted patterns existing between codes and clustered these related codes into groups. Again, this iterative process included merging some groups together, separating some groups into two distinct groups, and re-naming other groups. Thereafter, I created themes and sub-themes based on my interpretation of patterns existing between various groups. During the processes of theme formulation, I frequently met with my supervisors and colleagues to discuss the potential themes and sub-themes. Finally, I formulated a table of potential themes and sub-themes with their respective codes.

3.7.2.2.4 Reviewing themes. I revised the themes by reading the extracts of each theme to see whether the extracts formed a coherent pattern. If the extracts did not form a coherent pattern, I moved the unrelated extract to a more appropriate theme, or discarded the extract from the analysis. Additionally, I re-read the entire data set to assess whether the data supported the themes. Subsequently, I presented and then discussed the candidate themes and sub-themes with my supervisors. I then refined the themes based on my supervisors' comments and my critical reading of the extracts and the entire data set. Finally, I formulated an updated table of themes and sub-themes with their respective codes.

3.7.2.2.5 Defining and naming themes. Before naming the themes, I reviewed the extracts of each theme in an attempt to understand the essence of each theme. Thereafter, I defined each theme. Each definition included a detailed description of each theme, a narrative of how the extracts related to form a theme, and an explanation of how the theme served the broader analytic aim. Additionally, I began to formulate working headings of each theme.

3.7.2.2.6 Producing the report. I wrote a final report in which I presented an account of caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape. In this report, I described each theme, quoted selected extracts that illustrated the essence of each theme, analysed each quote in

order to highlight the significance of the theme, and indicated how each theme explained the overall analytic aim.

3.7.2.3 Preliminary analysis. In the preliminary analysis, I followed steps one to four of Braun and Clarke's six phases of coding and theme development. I did not follow these steps as rigorously in the preliminary analysis as I did in the final analysis. Specifically, I did not go back and forth between Braun and Clarke's phases as much as when I conducted the final analysis. Thereafter, I met with my supervisors to discuss the findings of the preliminary analysis and to identify areas in the discussion guide that could, based on the findings from the preliminary analysis, be improved. We acknowledged that the preliminary data were meaningful and would contribute to answering the research question. However, we realised that (i) I could adjust some questions in the discussion guide to elicit richer data and (ii) improve my analytic strategies for the final analysis in order to mitigate the chances of using data collection questions as themes. Some of the suggestions for adjusting the discussion guide included (i) making the questions more open-ended; (ii) providing the participants with more transparency about the research question; (iii) re-ordering the topic areas to start with the most relevant topic area first; and (iv) adding more probes to some of the questions. Specifically, I added more probes about the child's reactions to caregiver-child separation by drawing a timeline and asking caregivers to indicate how their child reacted at various stages in the separation process. More so, we asked caregivers and health workers for clarification about contradictory statements. Subsequently, I adjusted the discussion guide to incorporate the suggestions from my supervisors before returning to data collection (See Appendix C and D). Furthermore, in order to improve my analytic strategies, I focused on all of the data and not only elements of the data that answered the research question (Braun & Clarke, 2006).

3.7.2.4 Final data analysis. I followed Braun and Clarke's six phases of coding and theme development to guide the final analysis of the data. I followed the steps more

rigorously and systematically than in the preliminary analysis. As such, I went back and forth between the phases of initial coding, searching for themes, and reviewing themes in an iterative process.

3.8 Trustworthiness

Qualitative researchers use the criteria for trustworthiness to evaluate the rigour of a study (Nowell et al., 2017; Rubin & Babbie, 2009). The most widely accepted criteria for trustworthiness are: (i) credibility; (ii) transferability; (iii) dependability; and (iv) confirmability (Lincoln & Guba, 1985; Nowell et al., 2017). I now discuss how I achieved trustworthiness in this project.

3.8.1 Credibility. Credibility refers to the measures used to ensure agreement between participants' perceptions and the researcher's representation of their perceptions (Given, 2008; Tobin & Begley, 2004). In order to maintain credibility, I used triangulation by involving three different researchers in data collection (Nowell et al., 2017). This prevented undue influence on the data from a single researcher; ultimately increasing the legitimacy of the research findings (Lichtman, 2010).

Additionally, I used a two-stage analysis process to ensure credibility of this research study. This allowed me to adjust the data collection and analytic procedures for the second round of data collection and analysis based on lessons learnt from the preliminary analysis. This ensured that the data, produced in the final analysis, were significant and that the analytic procedures were rigorous (Glaser & Strauss, 1967).

Moreover, I regularly met with my research team, supervisors, and colleagues to discuss my interpretations of the data and to explore alternative interpretations of the data. This served as an external check to my interpretations (Nowell et al., 2017).

I also kept a research journal in which I reflected on my assumptions and values and how this may have influenced my interpretation of the participants' perceptions (Reid,

Greaves, & Kirby, 2017). In order to demonstrate credibility to external readers, I present a summary of my reflections in Section 4.4. In this reflective piece, I explain how my background, assumptions about the world, and social position (gender, race and social class) influenced the choice of research topic, the procedures of data analysis, and the interpretation of the data.

3.8.2 Transferability. Transferability refers to the degree to which the findings from one study in a specific context can be transferred to other settings (Drisko, 2013). To address transferability, I provided a "thick description" – a rich, detailed description of the sampling process, the participants in the study, the context in which the study was conducted, the procedures of data collection and analysis, and the findings. (Geertz, 1973, p.11; Lewis, Ritchie, Ormston, & Morrell, 2014; Nowell et al., 2017). This gives other researchers or readers the opportunity to decide for themselves whether the findings are transferable to the context of interest (Jensen, 2008). Additionally, I used my theoretically informed understanding of caregiver-child separation during long-term hospitalisation for MDR-TB to decide how far to extrapolate from the data (Toma, 2005).

3.8.3 Dependability. Dependability refers to research procedures that are consistent, reproducible, and traceable (Nowell et al., 2017; Pitney & Parker, 2009). In order to ensure that the research study is reproducible, I clearly described the systematic process of data collection and provided a translated, role-played, and iteratively-refined discussion guide.

In order to demonstrate dependability, I submitted various documents to show that the steps in the research project can be tracked (Nowell et al., 2017). I submitted the discussion guide (Appendix B), the adjusted discussion guide (Appendix C and D), and a record of the development of my themes and codes from the preliminary analysis to the final analysis (Appendix G). I also created anonymised records of all the forms of data, original data (audio recordings) and the transcripts, that are available upon request.

3.8.4 Confirmability. Confirmability means that the researcher's interpretation of the data is derived from the data (Nowell et al., 2017). I read the literature extensively, before and during data collection, in order to explore how other researchers interpreted caregivers' or health workers' perceptions about caregiver-child separation (Atkinson, 2008). The literature provided some guide about the type of patterns to look for in the data. Since, I have not had extensive experience working with caregiver-child separations, reading the literature helped to ensure that I was able to represent participants' perceptions of caregiver-child separation for MDR-TB more accurately.

3.9 Ethical procedures

In this study I maintained the principles of ethical social research outlined by Babbie and Mouton (2001). The research assistants and I explained these ethical principles in detail to the participants during the informed consent procedure. This was addressed in section 3.6.6 on 'Informed consent'.

3.9.1 Ethical clearance. Ethics approval for this study was granted by the Health Review Ethics Committee (reference number: S17/10/238; see Appendix H). I submitted this ethics application as a supplementary application to the original ethics application for MDR-PK II.

3.9.2 Confidentiality and anonymity. I respected participants' autonomy by maintaining that participation in the study was voluntary. I reminded participants that they could withdraw at any time. I kept all data confidential to the study team through appropriate security measures. Specifically, we locked hard copies of the consent forms in cabinets and stored soft copies of the consent forms, recordings, and transcripts on password-protected computers. Further, I anonymised any data presented publicly by removing all identifiers and replacing them with codes and/or pseudonyms. None but the interviewers and I knew the identity of the participant and all these parties were obligated to protect the confidentiality of

the participant's information. We would have only breached confidentiality if the researchers witnessed cases of abuse. In such cases, I would have followed the protocol recommended by DTTC. However, the researchers did not witness any cases of abuse.

3.9.3 Benefit and risk. The risk was minimal, corresponding with daily life or psychological examinations. Interviewers probed participants to think about caregiver-child separation, which mostly led to feelings of anxiety and distress. We also aimed to minimize the potential risks by referring participants for counselling for psychological distress. I discuss this further in section 3.9.4 on 'Referral'. Additionally, the benefit for participating in the research study was limited. There was no direct benefit for interviewees participating in this study asides from the opportunity to share the experiences with the research team. However, there was an indirect benefit from participating in the study. The participants had the opportunity to contribute to a study of value that will inform our understanding of MDR-TB treatment for their community of children and families affected by MDR-TB.

3.9.4 Referral. All researchers were trained to refer participants to the Wellgevallen Community Psychology Clinic at Stellenbosch University, Stellenbosch or to the social worker at BCH/TCH for free counselling for any psychological distress that they may have encountered, especially during the interview process. The researchers referred one participant to the social worker at BCH because she expressed significant distress during the interview. Furthermore, after the interview, participants were offered the opportunity to ask any questions.

3.9.5 Vulnerable population. The caregivers were considered a vulnerable population because they faced numerous socio-economic challenges. To ensure ethical treatment of this vulnerable group, I prevented possible undue influence by regularly checking in with participants to ensure that they understood that participation was voluntary.

3.9.6 Reimbursement. MDR-PK II reimbursed the participants for any incurred travel cost. We also offered participants lunch when coming to BCH for an interview.

3.10 Summary

In this chapter, I described the data collection and analytic procedures of this research project. I also explained the way in which I maintained ethical principles and enhanced the trustworthiness of the data.

Chapter 4: Findings

4.1 Introduction

This chapter introduces my key findings from 19 interviews with caregivers and health workers about their perceptions of the effects of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape. I begin this chapter by providing an overview of the sample by describing:

i. the demographics of the caregivers and health workers;
ii. the demographics of the children who were hospitalised long-term for MDR-TB; and
iii. the features of caregiver-child separation during long-term hospitalisation.

Thereafter, I present the findings, which I have organised into three major themes and various sub-themes. I define each theme and sub-theme and illustrate these themes with excerpts from the interviews. The three major themes include:

i. experiences of distress;
ii. children's behavioural and emotional states; and
iii. caregivers' and health workers' behavioural and emotional management strategies.

Finally, I present a reflexive piece, in which I address how my assumptions, background, and social position influenced the research project.

4.2 Description of the Participants

4.2.1 Characteristics of the sample. In total, we conducted 19 interviews: 12 interviews with caregivers and 7 interviews with health workers. We interviewed 14 caregivers in total because in two instances both the mother and father attended the interview. Furthermore, we conducted five interviews with the mother only and one interview with the father only. I present a summary of the demographic information of the participants (the

caregivers and health workers) in Table 1[4]. Of the seven health workers, three worked for MDR-PK II and four worked directly for BCH. One of the BCH health workers was a social worker while the other three delivered clinical care.

Table 1

Demographics of the Participants

Variable	Caregivers (n = 14)	Health workers (n = 7)
Gender		
Man	3	1
Woman	11	6
Race		
Coloured	10	4
Black	4	3

Between the 12 caregivers, they had 13 children hospitalised at BCH as one mother had twins. The mean and median age of the children was three years. Seven of the children were boys and six were girls. Eight of the children were coloured and five were black. I present a summary of the demographic information of the children in Table 2.

Table 2

Demographics of the Children

		Gender		Race	
Age (in years)	*n*	Boy	Girl	Coloured	Black
2	6	3	3	4	2
3	3	2	1	3	0
4	4	2	2	1	3
Total	13	7	6	8	5

[4] I included the race and gender of the participants because parenting and caregiving practices may differ across race and gender (Barnhart, Raval, Jansari, & Raval, 2013; Roman, Makwakwa, & Lacante, 2016).

4.2.2 Features of caregiver-child separation. The median age of admission to the hospitals was two years. The median duration of hospitalisation was three months. There were two outliers in this data set. A two-year-old boy was hospitalised for three weeks but did not experience caregiver-child separation as his mother stayed with him for the duration of hospitalisation. Additionally, a four-year-old boy had been in hospital for three years at the time of his interview. Most children had only been hospitalised once, but two children were hospitalised twice. I present a more detailed summary of the features of caregiver-child separation during long-term hospitalisation in Table 3.

Table 3

Features of Caregiver-child Separation

		Duration of hospitalisation[b]				Re-admission	
Age at admission[a]	N	No Separation	≤ 1 mo.	1 to 6 mos.	6 mos.- 1 yr.	≥1 yr.	Yes	No
≤ 1	4	0	0	2	1	1	2	2
2	7	1	2	4	0	0	0	7
3	1	0	0	1	0	0	0	1
4	1	0	1	0	0	0	0	1
Total	13	1	3	7	1	1	2	11

Notes. Wks.=weeks; Mo.= month; Mos. = months; yr.= year.

[a] The age of admission, for children who experienced repeated admissions, refers to their age at their first admission. [b] The duration of hospitalisation, for those who experienced repeated admissions, is the total time spent in hospital for both admissions. My rationale for including the total value is because the longer the hospital stay, the more likely the child is to experience the negative effects of caregiver-child separation during hospitalisation (Douglas, 1975; Vernon, Schulman, & Foley, 1966). For those children who were still in hospital at the time of the interview, this number refers to the total time they had been in hospital at the time of the interview.

Finally, in Table 4, I present the pseudonyms of the caregivers and children along with their demographic details. In this table, I also include information regarding the features of caregiver-child separation. Thereafter, in Table 5, I present the pseudonyms of the health

workers with their corresponding demographic details. Additionally, I include information about the health workers' employer and job title.

Table 4

Pseudonyms of Caregivers

Participant's code	Caregiver's pseudonym	Child's pseudonym	Child's gender	Child's age	Age at admission	Duration of hospitalisation	Re-admission
I1_A_Ca_W_Co	Ciara	Mathew	B	4 yr.	4yr.	1 mo.	No
I1_A_Ca_M_Co	Greg			(same as above)			
I3_A_Ca_W_Ca	Tiffany	Jerome	B	3 yr.	3 yr.	4 mos.	No
I3_A_Ca_M_Co	Jimmy			(same as above)			
I4_A_Ca_W_Co	Cathy	Caitlyn	G	2 yr.	2 yr.	1 mo.	No
I6_A_Ca_M_Co	Henry	Eben	B	4 yr.	1 yr.	> 6 mos.	No
I8_X_Ca_W_B	Khanyi	Zandile		2 yr.	2yr.	3 wks.[a]	No
I9_A_Ca_W_Co	Sally	Stephanie	G	3 yr.	1 yr.	3 mos.	Yes
I10_A_Ca_W_Co	Chantal	Gerald	B	2 yr.	1 yr.	3 mos.	No
I11_X_Ca_W_B	Pumi	Nomble	G	4 yr.	2 yr.	6 mos.	No
		Ntombentsha	G	4 yr.	2 yr.	6 mos.	No
I12_X_Ca_W_B	Ntombi	Abenathi	B	4 yr.	1 yr.	3 yr.	Yes
I14_A_Ca_W_Co	Connie	Nicolette	G	2 yr.	2 yr.	1 mo.	No
I15_A_Ca_W_Co	Ingrid	Evelyn	G	2 yr.	2 yr	3 mos.	No
I16_X_Ca_W_B	Mthobeli	Anathi	B	2 yr.	2 yr	2 mos.	No

Notes. I did not include the gender and race of the caregivers in this table because this information is present in the participant's code. Wks.=weeks; Mo.= month; Mos. = months; yr.= year/years

[a]Zandile was hospitalised for three weeks without caregiver-child separation.

Table 5

Pseudonyms of Health Workers

Participant's Code	Health worker's pseudonym	Health worker's employer	Health worker's job title
I2_E_HW_W_Co	Molly Smit	MDR-PK II	Research nurse
I6_E_HW_W_Co	Urma Jaivyn	MDR-PK II	Research counsellor
I7_E_HW_W_Co	Wendy Van Zyl	MDR-PK II	Research nurse
I13_E_HW_W_Co	Renata Voster	BCH	Clinical nurse
I17_E_HW_W_B	Noliswa Sisipho	BCH	Clinical nurse
I18_E_HW_W_B	Cebisa Jambase	BCH	Clinical nurse
I19_E_HW_M_B	Thobela Thabang	BCH	Social worker

Note. I did not include the gender and race of the health workers in this table because this information is present in the participant's code.

4.3 Themes

I analysed the data to describe and interpret caregivers' and health workers' perceptions of the effects of caregiver-child separation during long-term hospitalisation on children with MDR-TB. Using thematic analysis, I organised the data into three themes and various sub-themes as depicted in Table 6. In this section, I describe the themes and sub-themes in detail and present quotes from the data to support my explanations.

Table 6

Themes and Sub-themes

Theme	Sub-theme
4.3.1 Experiences of distress	4.3.1.1 Distress from MDR-TB medication
	4.3.1.2 Distress from caregiver-child separation
4.3.2 Children's behavioural and emotional states	4.3.2.1 Excessive crying
	4.3.2.2 Aggression
	4.3.2.3 Hyperactivity
	4.3.2.4 Withdrawal
4.3.3 Caregivers' and health workers' behavioural and emotional management strategies	4.3.3.1 Deception
	4.3.3.2 Threat
	4.3.3.3 Prioritisation of biomedical health over psychological health

4.3.1 Theme one: Experiences of distress. Health workers and caregivers described their experience of MDR-TB treatment as distressing. The participants highlighted that they perceived two componets of MDR-TB treatment to be particularly stressful: the medication and caregiver-child separation.

4.3.1.1 Distress from the medication. Caregivers and health workers reported experiencing high levels of stress during the administration of the anti-MDR-TB medication and from the adverse effects of the medication. Additionally, they reported perceiving children to experience distress from the administration of the anti-MDR-TB medication and from the adverse effects of the anti-MDR-TB medication.

4.3.1.1.1 Administration of the injection. Caregivers and health workers explained that children appeared to suffer from severe pain when receiving the injection. Children ran away from the health workers who were approaching them with the injection. Thereafter, children cried as the health workers administered the injection. Caregivers and health workers experienced distress when forcibly administering the injection to children who were crying

from pain. Connie [5], mother of Nicolette (admitted at: two yr.; hospitalised for: one mo.) described the stressful experience of administering the anti-MDR-TB medication. She said:

> If they now give her an injection or they give her medicine, uh she's two years, she cries. When she sees the name [of the medication] then I have to hold her down. That's not a nice thing to keep your own child down for a needle. Then she cries. Sometimes when I hold her down then she says: "don't mommy mommy don't keep me let me go mommy mommy the aunty is making me eina [meaning sore]". Sometimes, she swears … (I14__A_Ca_W_Co).

4.3.1.1.2 The adverse effects of anti-MDR-TB medication. Caregivers and health workers reported that they observed children suffering from the adverse effects of the medication. These included nausea, discoloured skin, numbness in their legs, and hearing loss. Caregivers were distressed at having to observe their children in pain and discomfort from these adverse effects. Pumi described the adverse effects that her children experienced while on anti-MDR-TB medication (admitted at: two yrs.; hospitalised for: six mos.):

> It's when I have been seeing them as if they are disabled. When they seemed to have changed now. They have radically changed the colour, while they are now taking up the treatment. They are different people – they seem to be like staggering like this. They have totally changed from who they are (I11_X_Ca_W_B).

In summary, caregivers, health workers, and children experienced severe distress as a result of the anti-MDR-TB medication.

[5] In addition to using pseudonyms to protect the identity of the participants, I also used pseudonyms to make the narratives more personal and easier for the reader to follow (Naccache, Kitzinger, & Samuel, 2013).

4.3.1.2 Distress from caregiver-child separation. Caregivers and health workers explained that caregiver-child separation during long-term hospitalisation caused them and the children overwhelming distress. Participants highlighted that children's behavioural and emotional state before, during, and after separation were indicative of their distress. Caregivers described that children cried on the way to the hospital. Additionally, caregivers and health workers explained that during hospitalisation, and for a few months after hospitalisation, children cried frequently, refused to eat, and depicted signs of depression. A health worker, Noliswa, addressed some of children's responses to separation. She said:

> They are depressed – crying non-stop. They can't sleep. Like you can see like they feel sick inside. Although they don't know what is happening, but just to be separated […] you can see say they are just being confused (I17_E_HW_W_B).

Moreover, caregivers expressed that they also felt stressed before, during, and after separation. Caregivers cried and protested in response to the doctor informing them about caregiver-child separation. A health worker, Wendy, described caregivers' responses to the doctor's feedback that their children had to be hospitalised long-term. She said:

> Wendy: No hysterical, most of them.
>
> Interviewer: What do they do cry or?
>
> Wendy: Some people cry. Some people I saw people fall on ground […]. I see people say: "no there's no way you [sic] going to do this we [are] not leaving our child" (I7_E_HW_W_Co).

Caregivers also described that they continued to experience distress throughout the period of caregiver-child separation. Caregivers felt anxious, and guilty while their children were in hospital. As a result of their stress, caregivers struggled to sleep and lost weight.

Pumi, a caregiver of twins (admitted at: two yr.; hospitalised for: six mos.), described the stress that she felt while her twins were in hospital. She said:

> I was not sleeping at night. I was always thinking. Then I had also lost weight. It was as if I am the one who was sick because I was not sleeping. I was always thinking about them (I11_X_C_W_B).

Caregivers' experiences of distress did not end when their children returned home. Many caregivers cried during the interview when they spoke about the separation, even though their children had already been discharged a few months previously. Jimmy, father of Jerome (admitted at: three yr.; hospitalised for: four mos.), cried as he described his experience of dropping his child at BCH. He said:

> Yes, from the time that we came here. People that came to fetch us at Tygerberg [Hospital] […]. So, he [Jerome] laid on [sic] slept on my lap. So, so I saw tears running out of his eyes, he probably felt that there [Jimmy started to cry] (I3_A_Ca_M_Co).

Moreover, children and primary caregivers were not the only family members to experience distress. Secondary caregivers, grandmothers, siblings, and neighbours cried, reminisced, and longed for the child who was hospitalised at BCH. An example of other family members' experiences of distress can be seen in a conversation with Ntombi, caregiver of Abenathi (admitted at: one yr.; hospitalised for: three yr.). Ntombi said:

> We have not yet, we have not yet, we have not yet, what will I say we are not yet recovered. Worse! While mother was still around I had come with those children of mine – the ones I said are at school. It was just screams hey [they] were crying at the securities [security guards] at the gate. And this one [Abenathi] was crying. [He was] climbing on the fence. He wanted Wandile [Abenathi's brother]. Then the older one [Wandile]

> turned back. The ten-year old one, he said: “I am going to stay together with Abenathi even if I have not eaten.” I said: “There is no bed for you over there” (I12_X_Ca_W_B).

Health workers also described their experience of caring for children who have been separated from their caregivers whilst in hospital as distressing. Wendy explained that many health workers were overwhelmed from working at BCH. She said:

> I think some of them ask to work there [BCH]. But there’s also some of them that say: “I really want to get out of here [BCH]”. Because mainly some of them, because they can’t [stand] seeing the children’s pain or crying or that all the time (I7_E_HW_W_Co).

In summary, health workers and caregivers described MDR-TB treatment as distressing. Specifically, participants expressed that the administration of the medication, the adverse effects of the medication, and caregiver-child separation were the most distressing components of MDR-TB treatment.

4.3.2 Theme two: Children’s behavioural and emotional states. Caregivers and health workers reflected on children’s behavioural and emotional states at different periods during MDR-TB treatment. These included excessive crying, aggression, hyperactivity, and withdrawal.

4.3.2.1 Excessive crying. Caregivers and health workers mentioned that children cried frequently during MDR-TB treatment. As mentioned previously, caregivers and health workers explained that children cried during the administration of the injection. Participants also emphasised that children cried excessively on admission, during visits from caregivers, during weekend visits at home, and after discharge when returning home. However, health workers mentioned that, after a few weeks in hospital, the children settled down in hospital and stopped crying.

Health workers explained that when children were admitted to BCH, they cried continuously. Noliswa described how children reacted to their caregiver's departure on admission day. She said:

> Noliswa: Yoh, it's a drama! [laughs]
>
> Interviewer: Really?
>
> Noliswa: [Laughs] Why they cry some of them! Some of them cry until they sleep (I17_E_HW_W_B).

Additionally, health workers explained that children's crying continued for about a week. Thereafter, children started crying again when their caregivers visited the hospital. Renata explained that the one baby in the ward was crying because she had just been admitted to hospital. Renata said:

> And that's the reason why she's continuing – crying crying crying. But um sometimes it takes like a week or sometimes, when the parents come again, it will stop. And then when the parents come again to visit and they must leave then it, it starts again (I13_E_HW_W_Co).

Participants also reported that children continued to cry after discharge when their children returned home. Caregivers did not attribute their children's tears to distress resulting from caregiver-child separation. Rather, they believed that their children were being disobedient. Henry described that after hospitalisation Eben (admitted at: one yr.; hospitalised for: > six mos.) cried excessively. Henry said: "Then he now wasn't the son I knew man. He was very naughty for me. He cries for anything. He was very glum" (I5_A_Ca_M_Co).

However, health workers explained that after a few weeks in hospital, children stopped crying and returned to their previous levels of happiness and playfulness. Health workers attributed these behavioural changes to children getting used to the hospital

environment. Molly, a health worker, explained that children stopped crying after a few weeks in hospital. She said:

> Um, I would say it's like once the child gets used to the environment here, used to the circumstances they would come in a way they would become little bit a happy child [sic]. […] And I think it's merely the fact that the child knows that I still have that security there (I2_E_HW_W_Co).

Another health worker, Noliswa, explained that children become happy after some time in hospital. She said:

> Yes, I think they get used to the food they get used to the tablets. They getting better, compare on admission you can see then they getting stronger [sic]. They are not sick, they are playful and some of them they are talkative. Ja, they learn a lot (I17_E_HW_W_B).

In summary, caregivers and health workers described that children cried continuously during MDR-TB treatment. They highlighted particular events during MDR-TB treatment that triggered children to cry; including admission to hospital, visits from caregivers, weekends at home, and returning home after discharge. However, health workers said that after a few weeks in hospital, children became accustomed to the hospital environment and stopped crying.

4.3.2.2 Aggression. Caregivers and health workers reported that they experienced children as aggressive during MDR-TB treatment. Caregivers and health workers explained that children enacted aggressive behaviours (such as hitting, swearing, and biting) towards their peers, siblings, and their caregivers. Khanyi described her son, Zandile's (admitted at: two yr.; hospitalised for: three wks. without caregiver-child separation), personality as aggressive. She said:

> Hm, the difference with him is he is outgoing and he likes hitting hm. He is always violent you see. He quickly gets upset – hits. If he wants something he will hit you. He only speaks once, if you don't pay attention, oh he will throw himself to the ground (I8_X_Ca_W_B).

Additionally, participants observed that children ignored and rejected their caregivers. Sally explained that Stephanie (admitted at: one yr.; hospitalised for: six mos.; hospitalised twice) was angry with her. She said:

> Sally: Yes, she mos [just] knew me that time when, then she wanted nothing to do with me.
>
> Interviewer: Do you think she is mad at you?
>
> Sally: I think so, because she didn't see my face for a week or so (I9_A_Ca_W_Co).

Additionally, Greg described that Matthew ignored him when he returned home after hospitalisation. Greg said:

> Greg: We tell him to come out but he just. You can call and he can sit there and when you call his name, he just focuses on the TV. So we thought, he couldn't hear. So we came here [to Tygerberg Hospital] for a hearing test and uh, the doctor said: "There's no problem he just doesn't want to listen to you."
>
> Interviewer: Oh so what do you think, what is your understanding of that?
>
> Greg: I think that was his way of of telling us, uh, let's say of he's not happy with us, leaving him there. See

because, he'll ignore us completely

(I1_A_Ca_M_Co).

Overall, caregivers and health workers described that children enacted aggressive behaviours such as hitting, shouting, and swearing during MDR-TB treatment. Furthermore, children rejected and ignored their caregivers during visitations and after being discharged. Caregivers understood this rejection as children continuing to harbour anger towards them.

4.3.2.3 Hyperactivity. Health workers explained that children became hyperactive after a few weeks in hospital. Additionally, caregivers expressed that when children were at home, for weekend visits or after discharge, children were very active and did not concentrate easily. A health worker, Wendy, explained that one of the caregivers, Ciara, described her son, Matthew (admitted at: two yrs.; hospitalised for: one mo.) as hyperactive. She said:

> She personally told me that she would have wanted to be with him every day but now that was mos [just] now [sic] not possible. And he was, he started, his behaviour changed in a sense that, in the sense that, his mom said he was like more "hyper" and more naughty (I7_E_HW_W_Co).

Chantal explained that her child, Gerald (admitted at: one yr.; hospitalised for: three mos.) was so difficult to manage during his first weekend visit at home that she took him back to BCH. She said:

> Chantal: That day my child was naggy, he was hysterical, he ran up and down I didn't know what to do
>
> Interviewer: Hysterical?
>
> Chantal: Up and down up and down up and down
>
> (I10_A_Ca_W_Co).

In summary, caregivers and health workers expressed that the children were hyperactive and difficult to manage during MDR-TB treatment.

4.3.2.4 Withdrawal. Caregivers and health workers explained that during hospitalisation, children were quiet and withdrawn. Ingrid expressed that her daughter, Evelyn (admitted at: two yr.; hospitalised for: three mos.) isolated herself at BCH. She said:

> She will just sit and look. This is one that is speechless because when I now go to her this afternoon then I peak through the window then I see everyone talks and so it's just her that sits and looks (I15_A_Ca_W_Co).

Molly, a health worker, also explained that during hospitalisation children were quiet and withdrawn. Molly said: "Ja, ja if the mom doesn't visit regularly the child misses the mom, you can see in the behaviour they just withdrawn, they crying, they agitated [sic], you know things like that" (I2_E_HW_W_Co).

Overall, theme two referred to caregivers' and health workers' descriptions of children's behaviours and emotional states during MDR-TB treatment. These included: excessive crying, aggression, hyperactivity, and withdrawal.

4.3.3 Theme three: Caregivers' and health workers behavioural and emotional management strategies. This theme refers to caregiving strategies used by caregivers and health workers in the context of MDR-TB treatment in the Western Cape. Health workers used deception and threat to ensure that caregivers adhered to the medication for their children. Moreover, caregivers and health workers used similar strategies of deception and threat to manage children's behavioural and emotional states during MDR-TB treatment. Additionally, caregivers and health workers prioritised children's biomedical health over their psychological health.

4.3.3.1 Deception. Health workers used deception to control caregivers' health-related behaviours. Similarly, caregivers used deception to control children's behavioural and emotional states during MDR-TB treatment. Health workers described that oftentimes clinic staff purposefully omitted information about caregiver-child separation when explaining the

MDR-TB treatment regimen to caregivers. They used deception to ensure that caregivers admitted their children to BCH for MDR-TB treatment. Renata, one of the health workers, explained that clinic staff deceived caregivers. She said:

> I think for, most of them, it's it's it's traumatic. Because sometimes even when they come, sometimes even when they, when they tell them on the other side the child must come here for like few months. Then it already, some of them even refuses. Sometimes it's so bad that they [nurses at the clinic] on the other side don't tell them that the child is going to stay here for such a long time, they just say, they coming [sic] to see the doctor. We had cases that come here. […] When they come here, then they surprised now to hear, that the child must be [hospitalised] (I13_E_HW_W_Co).

Caregivers deceived their children by leaving the hospital without saying goodbye. The use of deception by caregivers was encouraged by the health workers. Caregivers explained that they left without saying goodbye because they did not want to make their children cry. Ingrid reflected on how she left without saying goodbye to Evelyn (admitted at: two yr.; hospitalised for: three mos.). She said:

> Ingrid: Mm mm, I then never said that I am going home.
>
> Interviewer: Never said?
>
> Ingrid: Mm mm
>
> Interviewer: And then uh, how?
>
> Ingrid: I just told the doctor and the other nurse but I will now go home otherwise [inaudible words] she cries again (I15_A_Ca_W_Co).

In summary, health workers omitted information about caregiver-child separation in order to ensure that caregivers admitted their children to BCH. Additionally, caregivers did not say goodbye to their children because they wanted to prevent their children from crying.

4.3.3.2 Threat. Health workers used threat to control caregivers' and children's health-related behaviours. Specifically, health workers used threat to ensure that caregivers brought their children to BCH for treatment. Wendy explained:

> We, he [referring to a health worker] usually give them time [to decide whether they will admit their child at BCH]. He will always tell the parent: "It's your choice." Also, but you must also remember that he will [be sick/could die], if you don't want the child in the hospital it's actually, he will [tell] them: "It's actually abuse" because he will, ja, you take the right away of the child of [to] health care, so he will tell them (I7_E_HW_W_Co).

Additionally, health workers used threat to control children's behavioural and emotional states during MDR-TB treatment. Health workers threatened children with not going home for weekends or with an additional injection if they did not eat their food or take their medication. A health worker, Noliswa, used threat to ensure that children ate all their food. She said:

> Well we tell them "open" like we play with them and then tell them that: "After this you gonna get Danon [yoghurt] you gonna get sweets. I'm gonna buy you this. You must finish your food. You gonna [sic] go home see your mother. You gonna [sic] go for weekend. If you don't finish your food you [sic] not gonna go [home] for weekend" [laughs] you see ee ee or some of them I say: "I'm gonna give you injection" [laughs] I put the syringe here with water [laughs] just (I17_E_HW_W_B).

Moreover, caregivers used threat to discipline their children during MDR-TB treatment. After discharge, when caregivers struggled to manage children's behaviours, caregivers threatened to send their children back to BCH. Ciara described using threat to change Matthew's (admitted at: two yr.; hospitalised for: one mo.) behaviours. She said:

> Huh, mm just many times if he is naughty then I'll say: "I am going to take you to oupa's [referring to one of the senior health workers] hospital". The he will immediately then he will tell me he won't do it anymore (I1_A_Ca_W_Co).

In summary, health workers used threat to control caregivers' and children's health-related behaviours. Moreover, caregivers used threat to discipline children when their behaviours were difficult to manage.

4.3.3.3 Prioritisation of biomedical health over psycholoigcal health. Caregivers and health workers adopted a biomedical framework of health. Caregivers and health workers overlooked children's psychological experiences and in particular, children's negative psychological experiences. I observed caregivers and health workers adopting a biomedical framework of health when discussing (i) MDR-TB treatment and (ii) children's behavioural and emotional responses to MDR-TB treatment.

4.3.3.3.1 MDR-TB treatment. Caregivers and health workers prioritised children's biomedical health, by admitting them to hospital long-term for MDR-TB treatment. However, they acknowledged that by admitting the children to hospital long-term, they were neglecting children's psychological health by separating them from their caregivers. A health worker, Wendy, described Ciara's dilemma in terms of admitting Matthew (admitted at: two yr.; hospitalised for: one mo.) to hospital long-term. She said:

Wendy: She [the mother] said he [Matthew] actually [laughs] said that um um "jy gee my weg" ["you give me away"] you know […]

Interviewer: And what did she respond to that?

Wendy: Tearful, very tearful very emotional because she felt in a way it's true what the child is saying. But [it] was, was not in her hands and she felt also that she's like throwing her child away or, but on the one hand she said she had no choice it was the best for him that was her words then they just had to, to pull through and make this like work (I7_E_HW_W_Co).

Additionally, participants emphasised biomedical aspects of preparation for hospitalisation over psychological aspects of preparation for hospitalisation. Health workers explained that there were no established, psychological interventions to help children and their families prepare for the psychological distress resulting from MDR-TB treatment. Rather, health workers prepared caregivers for MDR-TB treatment by educating them about the biomedical components of MDR-TB treatment. A health worker, Cebisa, described the current practices used to prepare caregivers and their children for caregiver-child separation. Cebisa said:

> No, no I can't s- s- I can't say that, we, we prepare them yet, we only just give the, the education about the treatment about the the TB, about the accepting of separation, about the giving us the chance to be with the child so that the child can be, get better with the treatment (I18_E_HW_W_B).

Ntombi explained that she was more interested in Abenathi's (admitted at: one yr.; hospitalised for: three yr.) biomedical health than in an intervention that would help her manage her psychological distress. The interviewer asked:

> Interviewer: Maybe, what can you propose to be done in order to prepare before the child could go and stay at the hospital?
>
> Ntombi: Yoh, no sister there is none to me to me as long as Abenathi will be well (I12_X_Ca_W_B).

4.3.3.3.2 Children's behavioural and emotional responses to MDR-TB treatment.

When the interviewers asked caregivers if they observed any changes in their children after hospitalisation, caregivers referred to biomedical changes (for example, their children were healthy, or their children had gained weight) and did not focus on the psychological changes. For example, Jimmy described that the mucus in Jerome's chest increased (admitted at: three yr.; hospitalised for: four mos.). Jimmy said:

> Yes but then his chest started again – just constantly ge- threw up everytime, thre [threw] up. So, it was that bunch of mucus, that was on his chest and then that, that all that mucus that almost the whole night threw up threw up [sic] (I3_A_Ca_M_Co).

However, the interviewers then directly asked caregivers or health workers to describe the psychological changes that they noticed in the children. In response, caregivers and health workers either attributed biomedical factors to be the cause of the psychological changes or they only referred to positive psychological changes. Molly (a health worker) expressed that the MDR-TB medication caused children to become depressed. She said:

> Yes, it does affects [sic] their emotions. I mean the medication makes them nauseous. Sometimes it can affect them emotionally [sic]. You'll be

> surprised but you'll have, little children that shows signs of um, depression (I2_E_HW_W_Co).

Ntombi described Abenathi's (admitted at: one yr.; hospitalised for: three yr.) behaviour using positive descriptors. She said:

> His behaviour – he listens now. Abenathi usually doesn't listen. But even if he doesn't listen, a child would never really listen – all children do mess up. But he is not the same as before and he['s] even playing with other children. He does play. Of which for example, sometimes he would just stay at home but now you would find him looking around for children to play with (I12_X_Ca_W_B).

However, in cases where the interviewers asked caregivers directly about negative changes in their children's behaviour, caregivers would explicitly state that they did not observe negative changes. Alternatively, caregivers did not answer the. However, later in the interviews, these caregivers indirectly referred to negative changes in their children's behaviours. The interviewer asked Chantal:

> Interviewer: You've mentioned positive ways that have helped him, to become more independent, but do you think there were negative things?
>
> Chantal: Like I said, I did my best. I was there, but I could not, because he, they must sometimes draw blood a needling [sic] must go in, he did cry. I could not be there because it was for his own good, like I said it was for his own good (I10_A_Ca_W_Co).

However, later in the conversation, the interviewer asked Chantal how Gerald reacted on his first weekend at home and she explained:

Chantal: He was just, he was naggy and I took it I could not [sic]: "I cannot handle you because I don't know you are now at the moment you're another person."

Interviewer: Is it?

Chantal: "You're not my child, that I had, when you, before you got sick now" (I10_A_Ca_W_Co).

In summary, caregivers and health workers emphasised biomedical health over psychological health in terms of MDR-TB treatment and children's responses to hospitalisation. However, when caregivers and health workers were asked directly to describe the psychological changes that they observed in children, they either attributed underlying biomedical causal factors to explain the psychological changes. Alternatively, they only highlighted positive psychological changes to their children's behaviour.

4.4 Reflexivity

In this reflexive account, I address the possible influence of my background, assumptions about the world, and social position (gender, race, and social class) on the research project (Malterud, 2001; Oliver, 2013). I begin this reflexive account by describing my ontological and epistemological assumptions as well as my background and social position. I then reflect on how this shaped (i) the choice of research topic, (ii) the data collection procedures, (iii) how the participants answered the research questions, and (iv) the interpretation of the data.

4.4.1 My ontological and epistemological assumptions. I adopted the ontological assumption of critical realism. According to critical realism, external reality exists, but personal assumptions and socially constructed meanings shape perceptions of reality. As a result, reality in its purest form is inaccessible (Ormston, Spencer, Barnard, & Snape, 2014). Throughout my research project, I held that caregivers and health workers' perceptions of

caregiver-child separation provided access to a particular version of their experiences of caregiver-child separation. Caregivers' and health workers' personal values as well as society's constructions of caregiving and caregiver-child separation shaped their perceptions.

I adopted the epistemological assumption of interpretivism. According to interpretivism, the researcher interprets the world through the participants' and their own perspectives (Snape & Spencer, 2013). I understood caregivers' and health workers' perceptions of caregiver-child separation through my interpretation of their interpretations of their experiences (Snape & Spencer, 2013). In this section, I expand on my values and perspectives in order to provide transparency about how I interpreted the participants' perceptions (Snape & Spencer, 2013).

4.4.2 My background and social position. I am a 26-year old woman born in South Africa. Although, I was born as apartheid was ending, I grew up in the aftermath of apartheid; a period in which racial segregation and discrimination still exists (South African Human Rights Commission, 2018). As a child, I lived in an affluent, predominantly white suburban area in Johannesburg. I attended a Jewish day-school which was attended by mostly white students. As a result, I had little interaction with people from other cultures or racial groups.

However, during high school I attended a leadership programme, which facilitated the building of relationships between people of different cultural and racial backgrounds. During this programme, I was also involved in community work and learnt more about the inequalities in South Africa. Although, I learnt a lot from this programme, I do not purport to ever truly understand what it is like to be black or coloured in South Africa.

4.4.3 Research topic. I first thought about conducting research on this topic when I was attending a talk, as an employee at DTTC, by the Principal Investigator of MDR-PK II. He mentioned that children with MDR-TB are separated from their caregivers due to long-

term hospitalisation for MDR-TB treatment. He explained that some caregivers complained that, after discharge, their children were hyperactive. Immediately, I felt compelled to conduct research on whether these children were negatively affected by caregiver-child separation. When reflecting further on the reasons for my choice of topic, I observed that my strong desire to pursue this research project was motivated by a personal resonance to this topic based on past experiences.

My awareness of my privilege has driven a desire to help those who have been previously disadvantaged. I believe that the psychological well-being of children with MDR-TB in the Western Cape has been neglected because they are poor. This too has motivated me to conduct a research project on caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.

4.4.4 Data collection procedures. When reflecting on the data collection procedures, I became aware that I automatically assumed that caregiver-child separation affected all children negatively. By blindly holding this assumption, I might not have formulated all the questions as neutral. For example, I asked the question: “After one month in hospital, how did his/her behaviour change?” This question assumes that there were behavioural changes. I could have asked the question in a more neutral way: “After one month in hospital, please describe what you noticed about your child”. In order to manage this, when I analysed the data, I examined how my phrasing of the questions may have shaped the participants’ answers. I will discuss this assumption about caregiver-child separation further in section 4.4.6 on ‘Interpretation of the data’.

4.4.5 Participants’ responses to the research questions. My social position largely differed from the participants in terms of race, culture, level of education, and social class. Additionally, the participants spoke isiXhosa or Afrikaans; whereas I am only fluent in English. I wondered whether my presence (as a result of some of these differences) might

have made the participants less comfortable. As a result, this may have influenced what the participants chose to communicate during the interview and what they chose to hold back. In order to manage the participants' potential discomfort, I tried to create a comfortable environment by being friendly and warm. However, in some instances my role as an outsider appeared to be beneficial as it permitted me to ask additional questions of clarity about perceptions which are typically regarded as 'normal' to the participants or other members of their social group.

Additionally, I reflected that the participants might have interpreted some of the research questions as critical or judgemental of their caregiving practices. For example, it seemed as if parents felt as if they were being accused of causing their children long-term problems. Additionally, health workers also appeared to interpret the questions as if I was judging them for endorsing caregiver-child separation. This may have prevented participants from being completely transparent. In order to prevent participants from feeling judged, I started to preface some questions by explaining that I was not interviewing them to evaluate their caregiving practices.

4.4.6 Interpretation of the data. When analysing the data, I initially assumed that the children felt abandoned and rejected by their caregivers. When reflecting on this interpretation, I observed that I might have been biased in my expectation of what children might feel if they experienced caregiver-child separation. This prevented me from being open to the authentic experiences of the children as reported by the caregivers and health workers. In an attempt to mitigate these biases, I regularly debriefed with my supervisors and colleagues who provided alternative interpretations and reminded me to be aware of my own biases and assumptions. This external checking ensured that I analysed the data in a critical and systematic manner (Malterud, 2001; McLeod, 2011).

Additionally, I have read extensively and attended workshops and courses relating to attachment theory and child development. This theoretical understanding helped to prevent over-interpretation of the data based on personal experiences.

Chapter 5: Discussion

In this chapter, I highlight the main findings of my study and discuss them in relation to the reviewed literature. I present the strengths and limitations of my study. Lastly, I will provide recommendations for future research and the conclusion.

5.1 Summary of the Findings

In this study, I have explored caregivers' and health workers' perceptions of the effects of caregiver-child separation on children during long-term hospitalisation at BCH. I found that children, their caregivers and their health workers experienced distress during MDR-TB treatment. Specifically, caregivers and health workers reported that the administration of the medication, the adverse effects of the medication, and caregiver-child separation were distressing components of MDR-TB treatment. Children's behaviour and emotional states during MDR-TB treatment included: continuous crying, bouts of aggression, hyperactivity, and withdrawal. Additionally, caregivers and health workers used the following behavioural and emotional management strategies during MDR-TB treatment: deception, threat, and the prioritisation of biomedical health over psychological health.

5.2 Factors Contributing to the Difficulties Experienced by Children, Caregivers and Health Workers during MDR-TB Treatment

The difficulties experienced by children, caregivers and health workers during MDR-TB treatment most likely result from a complex interplay between precipitating, predisposing and maintaining factors. It is possible that MDR-TB treatment precipitated the onset of the distress, the behavioural problems and the behavioural and emotional strategies used in this study. However, predisposing factors such as social adversity also appeared to have contributed to the problems that emerged during MDR-TB treatment. Thereafter, the problems were likely maintained by children's coping mechanisms, children's persisting

behavioural problems and caregivers' continuous use of caregiving strategies that reinforced children's difficult behaviours.

5.2.1 Precipitating factors. Paediatric MDR-TB treatment could be considered an acute life stress precipitating the onset of (i) children's, caregivers', and health workers' experiences of distress (ii) children's behavioural and emotional problems, and (iii) caregivers' and health workers' use of deception, threat and the prioritisation of biomedical health over psychological health. Specifically, caregiver-child separation, hospitalisation, and anti-MDR-TB medication are components of MDR-TB treatment that could be regarded as precipitating factors.

5.2.1.1 The influence of precipitating factors on experiences of distress. Caregivers and health workers highlighted that caregiver-child separation, the adverse effects of the medication, and the administration of the medication were stressful components of MDR-TB treatment. These results echo findings from two studies conducted in South Africa on the psychosocial impact of MDR-TB treatment. Caregivers described the psychological distress resulting from caregiver-child separation during long-term hospitalisation, the adverse effects of the medication (e.g. stomach pain and dizziness), as well as from perceived stigma and the financial burden of the disease (Franck et al., 2014; Loveday et al., 2018). It is highly likely that, in addition to caregiver-child separation, others factors during hospitalisation contributed to children's, caregivers' and health workers' experiences of distress. Some of these factors may include: medical procedures (for example, blood tests, x-rays and injections), long-term hospitalisation, and the experience of having MDR-TB (Rokach, 2016).

5.2.1.2 The influence of precipitating factors on children's behavioural and emotional problems. Caregivers and health workers reported that during MDR-TB treatment, children cried continuously and were aggressive, hyperactive, and withdrawn. These

behaviours were similar to those identified by Spitz (1945, 1946) as well as Robertson and Bowlby (1952) in their studies on caregiver-child separation. Therefore, it is very possible that caregiver-child separation contributed to children's development of behavioural and emotional problems.

Firstly, children's excessive crying and withdrawn behaviours were similar to the symptoms of the children in Spitz's study (1945, 1956) who had spent one year separated from their caregivers whilst in a foundling home. However, unlike the children who developed physical disabilities after three years in the foundling home in Spitz's (1945, 1946) study, most participants did not report observing disability in their children. Only one participant (Pumi) described that her children looked disabled. However, Pumi's children were seemingly limping because of numbness in their legs from the injection. These differences in findings might be explained by the duration of separation and level of deprivation. Children in the current study typically spent three months at BCH as opposed to children in Spitz's (1946, 1946) study who had spent three years in the foundling home. Additionally, children in the current study experienced maternal deprivation and not complete emotional deprivation as seen in Spitz's (1945, 1946) study.

Secondly, the behavioural and emotional states observed in children were similar to children's responses to caregiver-child separation identified by Robertson and Bowlby (1952) namely: protest, despair, and detachment (Van der Horst, 2011). Participants in the current study explained that children cried loudly when they were admitted to BCH. Similarly, Robertson and Bowlby (1952) explained that in the first phase (protest) children's responses to caregiver-child separation consisted of loud crying (Van der Horst, 2011).

Moreover, caregivers and health workers explained that during MDR-TB treatment, children were withdrawn and isolated. Similarly, Robertson and Bowlby (1952) described that, in the despair phase, children were quiet and withdrawn (Van der Horst, 2011).

Health workers explained that after some time in hospital children stopped crying and were playful and happy. Robertson and Bowlby (1952) emphasised that if separation was prolonged, children entered into the phase of detachment during which children smiled often and appeared sociable (Van der Horst, 2011). However, Bowlby theorised that children were not getting used to the distress of separation and hospitalisation, rather children were detaching emotionally in order to cope with the distress (Barrett, 2005; Bowlby, 1969; Leifer, 2015; Sanders, 2014; Tiltman, 1984).

However, caregivers and health workers reported that children continued to cry after discharge when they were reunited with their caregivers. These findings are dissimilar to the findings by Robertson and Bowlby (1952). According to Robertson and Bowlby (1952), children in the despair phase responded to reunion with their caregivers by crying (Leifer, 2015). However, children who experienced prolonged separation (like children at BCH) and who were in the detachment phase, were indifferent to reunion with their caregivers (Allen, 2018). The current study did not have sufficient evidence to make conclusions about the reasons for children's crying after discharge. Future research should explore the reasons for children's crying after discharge.

Additionally, caregivers and health workers reflected that children displayed aggressive behaviours (such as hitting, biting, and swearing) as well as hyperactivity. These behaviours also did not conform to Spitz's (1945, 1946) hospitalism and anaclitic depression as well as Robertson and Bowlby's (1952) protest-despair-detachment model. Nonetheless, in other hospitalisation and separation research, children hospitalised for more than one week developed behavioural and psychological problems such as aggression and hyperactivity (Hollenbeck et al., 1980; Illingworth & Holt, 1955; Prugh et al., 1953; Vernon et al., 1966).

The models of behaviour presented by Spitz (1945, 1946), and Robertson and Bowlby (1952) might not have predicted behaviours such as aggression and hyperactivity because

they did not account for other contributing factors besides for caregiver-child separation. The models by Spitz (1945, 1946), and Robertson and Bowlby (1952) did not account for individual differences in children (for example, a child's history with their primary caregiver and the age of the child; Barrett, 1997; James, Nelson, & Ashwill, 2012) or the context of the child (Chess & Hassibi, 2013). It is very likely that predisposing factors, such as individual differences in the child or the context of the child, might explain children's aggression and hyperactivity. These factors will be explored in more detail in section 5.3.2 on 'Predisposing factors'.

It seems likely that caregiver-child separation during long-term hospitalisation for MDR-TB treatment contributed to children's development of behavioural and emotional problems. However, children's behavioural and emotional states during hospitalisation are inextricably linked to other precipitating factors during hospitalisation (for example, medical procedures) as well as predisposing factors (for example, social adversity) (Barrett, 1997; Chess & Hassibi, 2013; Eysenck, 2005; James et al., 2012; Rokach, 2016).

Furthermore, Melnyk (2000) argued that children's behavioural and emotional responses to hospitalisation, if used temporarily, were healthy responses by children to cope with a stressful situation. For example, some children detached emotionally to cope with the stress of their need for their caregivers not being met (Barrett, 2005; Bowlby, 1969; Leifer, 2015; Sanders, 2014; Tiltman, 1984). In the context of MDR-TB treatment, children's behavioural and emotional responses were likely adaptive strategies to hospitalisation amongst other stressors such as social adversity.

5.2.1.3 The influence of precipitating factors on the types of behavioural and emotional management strategies used by caregivers. It is likely that caregivers used the strategy of threat because of the stress resulting from caregiver-child separation during long-term hospitalisation for MDR-TB. In previous research, caregivers living with HIV were less

likely to engage in positive parenting practices due to their high levels of anxiety regarding their health (Murphy, Marelich, Armistead, Herbeck, & Payne, 2010; Sherr et al., 2017). Similarly, it appears that, caregivers in the current study might have been overburdened by anxiety around their children's illness that they lacked the emotional resources required for tolerant, warm, and sensitive caregiving practices (Murphy et al., 2010; Sherr et al., 2017).

Furthermore, prior research suggests that in the context of caregiver-child separation during hospitalisation, caregivers used deception as a strategy to reduce the amounts of distress experienced by them and their children (Sanders, 2014; Tiltman, 1984). This explanation of deception provides a possible reason for caregivers deceiving their children by leaving BCH without saying goodbye. Caregivers might have used deception as a strategy to avoid crying and distress that might have occured when saying goodbye.

In summary, MDR-TB treatment might have been a precipitating factor leading to children's and caregiver's experiences of distress, children's development of behavioural and emotional problems, and caregivers' use of deception and threat. Components of MDR-TB treatment that likely contributed to the development of these problems included caregiver-child separation along with other factors such as long-term hospitalisation, medical procedures, the unpalatable nature of the medication and the experience of having MDR-TB.

5.2.2 Predisposing factors. In addition, predisposing factors could also have been instrumental in the development of children's behavioural and problems and caregivers' and health workers' use of deception, threat and the prioritisation of biomedical health over psychological health; Carr, 2005). In the context of the Western Cape, conditions of adversity (for example, exposure to poverty and violence) most likely served as predisposing factors.

5.2.2.1 The influence of predisposing factors on children's development of behavioural and emotional problems. Factors such as social adversity likely predisposed the children at BCH to developing behavioural and emotional problems (Henderson & Martin,

2014). In a study conducted in Khayelitsha in the Western Cape, 25% of children were classified as having a disorganised attachment pattern (Tomlinson, Cooper, & Murray, 2005). A disorganised attachment pattern is characterised by various conflicted and fearful behaviours, for example, crying, hitting, freezing and displaying fear of their caregivers (Granqvist et al., 2017; Walker & Crawford, 2014). These behaviours are similar to some of the behaviours identified in children at BCH. Disorganised attachment often occurs in the context of family abuse or violence. In the Western Cape (particularly in Khayelitsha) there are high rates of domestic violence (Petersen, 2015). Therefore, it seems likely that disorganised attachment patterns explain some of the behavioural problems seen in children who were hospitalised for MDR-TB at BCH.

In addition, in the Western Cape, it is common for children to be exposed to violence (including school violence, neighbourhood violence, gang violence, and police violence; Isserow, 2005; Shields, Nadasen, & Pierce, 2008). Previous research suggests that such exposure to violence contributes to childhood aggression (Aitken & Seedat, 2007; Merwe & Dawes, 2009). Therefore, some of the childhood aggression observed by caregivers and health workers may be explained by the children's previous exposure to violence.

Caregivers and health workers also explained that children grew up in a setting characterised by limited resources. The exposure to the stressors of living in poverty may explain some of children's behavioural and emotional problems (Carr, 2005; Wadesango, Chabaya, Rembe, & Muhuro, 2011). This is in line with previous research in which poverty and related factors (such as access to safety and education, and limited resources) contributed to behavioural problems (such as anti-social behaviour) in children (Wadesango et al., 2011). Therefore, it is likely that children hospitalised for MDR-TB at BCH had prior experiences before hospitalisation that contributed to their development of behavioural and emotional problems.

5.2.2.2 The influence of predisposing factors on the types of behavioural and emotional management strategies used by caregivers and health workers. In the context of MDR-TB in the Western Cape, caregivers managed their children's behaviour and emotions by using the following strategies: deception, threat and the prioritisation of children's biomedical health over their psychological health. Moreover, when the researchers probed caregivers to discuss children's psychological responses to hospitalisation, caregivers highlighted positive psychological responses to separation and hospitalisation. These findings are similar to findings from previous studies, in which caregivers in South Africa used the following caregiving strategies: harsh parenting (Gould & Ward, 2015), manipulation and aggression (Bhana et al., 2004), and denying children's negative psychological experiences (Bain & Richards, 2016). It might be the case that caregivers in the South African context used these strategies because they were preoccupied with the stressors of living in poverty that they lacked the psychological capacity for emotionally sensitive and warm caregiving practices (Bain & Richards, 2016; Ward, Makusha, & Bray, 2015).

In the context of poverty, these caregiving strategies may be adaptive. For example, harsh parenting appeared to be adaptive in the context of poverty because it allowed parents to have control over their children to protect them from dangerous situations in harsh circumstances (Coltrane et al., 2008). Caregivers also appeared to deny their children's negative psychological experiences as a strategy to train their children that negative emotions were not useful in a context that was emotionally overwhelming and lacking in psychological support (Bain & Richards, 2016; Crittenden, 2000).

However, to attribute caregivers' descriptions of the positive effects of hospitalisation on their children only to the adpative strategy of denial is problematic. One has to hold the possibility that caregivers observed positive effects of hospitalisation on their children. For example, Ntombi described that Abenathi became more attentive and sociable during

hospitalisation. This hypothesis is supported by Hueckel's (2015) argument that long-term hospitalisation gives children the opportunity to develop resilience as children learn to master the ability to cope with stress and expand their interpersonal relationships.

Similarly to caregivers, health workers also used deception, threat and the prioritisation of biomedical health over psychological health to manage the behaviour and emotions of children and caregivers during MDR-TB treatment. These findings are comparable to a study conducted by Petersen (2000) at a community health centre in KwaZulu-Natal. Petersen (2000) observed that health workers avoided discussing their patients' psychological complaints and they provided biomedical explanations for their patients' psychological complaints (Petersen, 2000). Health workers in the South African context most likely prioritised the biomedical health of their patients over their psychological health because of a lack of training in the provision of mental health care (Petersen, 2000). Furthermore, in an under-resourced context, it is very possible that it is an effective strategy to prioritise the patient's biomedical health over their psychological health to ensure that limited resources are prioritised for the patient's survival (Sargent, 2010; Singh & Singh, 2008).

It might also be the case that this strategy is effective in protecting health workers from the anxiety that might emerge when working with children who are suffering from a dangerous disease such as TB (Van Der Walt & Swartz, 2002). Van Der Walt and Swartz (2002) applied Menzies Lyth's theory of defences against anxiety to health workers' management of TB patients at a public health centre in the Western Cape. Menzies Lyth (1999) explained that health workers who work in stressful situations develop coping mechanisms (for example, denial of feelings) to manage their stress and anxiety (Van der Walt & Swartz, 1999; Van Der Walt & Swartz, 2002). Van Der Walt and Swartz (2002) stated that "it is safer for nurses to acknowledge the control of the disease and the bacteria,

than to open themselves up to the illness experience and the human needs of the person" (p.1006). Therefore, it is reasonable to assume that health workers adopted the strategy of prioritisation of biomedical health over psychological health to protect themselves against the anxiety of working with children who have MDR-TB.

Health workers at a community health centre in KwaZulu-Natal also used strategies of coercion to control patients' behaviours (Petersen, 2000). This is similar to the way health workers used threats to ensure that caregivers and their children adhered to the MDR-TB treatment. Health workers in South Africa may utilise coercion or threat because they are over-worked and might not have the psychological capacity and time to use positive caregiving strategies (Petersen, 2000). Additionally, in a context that is already overwhelming with little emotional support, using threat may be regarded as an effective strategy to ensure adherence without having to understand and address patients' reasons for poor adherence (Petersen, 2000).

In summary, factors relating to conditions of adversity (for example, poverty and violence) likely predisposed children to developing behavioural and emotional problems. Additionally, similar predisposing factors most likely contributed to caregivers' and health workers' use of strategies such as deception, threat and the prioritisation of biomedical health over psychological health.

5.2.3 Maintaining factors. It is possible that children's behavioural and emotional problems were maintained by coping mechanisms or caregiving strategies that reinforced their behaviours (Carr, 2005). Furthermore, caregivers' use of harsh caregiving strategies were likely maintained by children's persisting post-hospitalisation behaviours (Patterson, 2002). I provide two examples to show how maintaining factors may have perpetuated children's behavioural and emotional problems and caregivers' use of harsh caregiving strategies.

The first example shows how coping mechanisms and caregiving strategies could have contributed to the maintenance of children's behavioural and emotional problems. Bowlby (1969) postulated that children who experienced prolonged separation coped with the emotional pain associated with their need for comfort from their caregiver not being met by detaching emotionally. Bowlby (1969) observed that these children usually appeared apathetic to their caregivers' presence when they visited. Caregivers often misinterpreted children's apathy as children's disinterest in them and, as a result, visited their children less frequently (Cassidy & Shaver, 2002). Caregivers' lack of visits might have perpetuated children's need to detach emotionally and as a result perpetuated behavioural and emotional problems in children such as withdrawal and lack of trust in others (Abell & Napoleon, 2007; Merck & McElfresh, 2016). Therefore, children's coping mechanisms and caregivers' misinterpretations of children's behaviours seemed to result in a vicious spiral perpetuating children's behavioural problems (Merck & McElfresh, 2016).

Secondly, after discharge, many children in the sample cried continuously. Caregivers threatened to send their children back to BCH if they continued to cry. Harsh parenting, such as the use of threat, has been shown to reinforce children's feelings of abandonment, which in turn perpetuates children's crying (Sigelman & Rider, 2018; Simons & Johnson, 1996). Furthermore, children's crying post-hospitalisation has been shown to contribute to caregivers feeling overwhelmed which usually makes caregivers more inclined to use harsh caregiving strategies (Sigelman & Rider, 2018). Therefore, children's behavioural and emotional responses to caregiver-child separation and caregivers' use of harsh caregiving strategies most likely interacted reciprocally to reinforce children's crying and caregivers' use of threat (Zuckerman & Keder, 2015).

In summary, MDR-TB treatment (including caregiver-child separation, long-term hospitalisation and medical procedures) can be understood as a precipitating factor which

triggered the onset of difficulties during MDR-TB treatment. Nonetheless, predisposing factors (for example, living in poverty and exposure to violence) likely contributed to the development of these problems. Lastly, children's coping mechanisms, children's post-hospitalisation behavioural problems, and caregivers' behavioural and emotional management strategies likely served as maintaining factors perpetuating these problems.

5.3 Strengths and Limitations of the Study

I discuss the strengths of the study alongside the study's limitations. A strength of the study is the study's relevance and timeliness. There is limited knowledge on the psychological impact of MDR-TB treatment (Hoddinott & Hesseling, 2018). In my review of the literature, the only study that addressed the psychological difficulties of MDR-TB treatment in the Western Cape was the study by Franck and colleagues (2014). However, Franck and colleagues (2014) explored caregivers' and children's experiences of MDR-TB treatment more generally and did not focus on caregiver-child separation due to long-term hospitalisation.

Another strength of the study is related to my sampling strategy. I attempted to recruit every member of the population of caregivers of children (aged zero to five years) hospitalised at BCH at the time of my data collection. I interviewed all caregivers of children who were MDR-PK II participants, hospitalised for MDR-TB at BCH at the time of my data collection, and who agreed to participate in the study.

However, a sampling method is always limited to participants who agree to participate in the study. The research counsellors reported that a few caregivers never answered their phones. Since I could not include caregivers in my sample who were unavailable, my sample was not representative of all caregivers of children hospitalised for MDR-TB treatment in the Western Cape. It is possible that caregivers who did not answer

their calls had a different experience of child-caregiver separation during hospitalisation, which may have precipitated a disengagement from contact with BCH, to those I interviewed.

It is a limitation to this study that more than one researcher was part of the data collection procedure. The researchers' values, assumptions, beliefs, and social position may have influenced the way in which the researcher asked questions (Given, 2008; Macfarlane, 2016). As a result, not all questions and probes were formulated consistently across the interviews. In order to manage this limitation, I attended all interviews. This allowed for the research assistant, who was conducting the interview, to ask me any questions about uncertainties that arose during the interview.

Moreover, the venue of the interview was at BCH or TCH, which is not a neutral space. This is a limitation for the study because participants might not have felt comfortable expressing critical views about MDR-TB treatment for fear that a health worker may eavesdrop during the interview (Powell & Single, 1996). Additionally, participants' responses might have been shaped by unequal power dynamics present in a medical setting in which the participant was previously a patient submitting to a doctor who had more knowledge and power (Charles, Whelan, & Gafni, 1999). In order to manage this limitation, I conducted all interviews in a private venue. Additionally, I attempted to neutralise the power imbalances present in the interviews by reinforcing that there were no right or wrong answers.

Another limitation is that due to the distressing nature of the interviews, interviewers tried to help participants answer difficult questions by re-framing open-ended questions as closed-ended questions. For example, a researcher may have re-framed the question "Did you notice any changes in your child's behaviour since hospitalisation?" to a question that probed the participant to think about a specific, leading example of a behavioural change such as "Was your child maybe more angry with you after hospitalisation?" This might have limited

or constricted participants' answers. In order to manage this limitation, I analysed the data by looking at how the questions shaped the participants' answers.

Another methodological limitation of my study is that I analysed the data from translated transcripts. All the interviews with caregivers were originally conducted in Afrikaans or isiXhosa. Some of the nuanced meaning of the data may have been lost in translation.

5.4 Future Recommendations

The findings from this study have highlighted that disruptions in the caregiver-child relationship during long-term hospitalisation for MDR-TB may be the cause of children's, caregivers' and health workers' experiences of distress. Furthermore, it is possible that caregiver-child separation triggered the onset of behavioural problems in children and the use of coping strategies by caregivers and health workers. In order to make recommendations for future policy and practice, it is useful to learn from the United Kingdom's (UK) transformation of childcare in hospitals. In the UK in the 1950s, based on Bowlby and Robertson's pioneering findings, Bowlby and Robertson (together with doctors, other researchers, and parents) put pressure on the medical establishment to make changes to hospital policies for children (Smith, 2015). The government established a committee to construct the Platt Report; a report presenting recommendations for hospital authorities on how to care for children during hospitalisation (Smith, 2015). The main recommendations from the report included:

i. Children should be hospitalised only when necessary and for the minimum length of time (Moules & Ramsay, 1998).
ii. Prior to admission, children and their families should attend an open-day. At the open-day, doctors should prepare children and their families for the hospitalisation and medical procedures (Meadows, Humphreys, & Billson, 2000).

iii. During hospitalisation, and where possible, primary caregivers should be admitted with their children. There should be unrestricted visiting hours for secondary caregivers. Children should be allowed to keep their own possessions (for example, toys and clothes). Health workers should try to maintain children's home routine. Health workers should attend training on how to address the emotional needs of children during hospitalisation (Meadows et al., 2000; Moules & Ramsay, 1998).

iv. On discharge, health workers should prepare primary caregivers for the potential outcome of children developing behavioural problems because of hospitalisation. Health workers should suggest ways to manage these behavioural problems (Meadows et al., 2000).

Based on insights from the Platt report, researchers explored the effectiveness of interventions to reduce children's, caregivers' and health workers' distress during hospitalisation. Interventions were offered at different stages of hospitalisation (Weaver & Groves, 2010). Pre-admission interventions such as home visits by health workers and orientation days offering tours of the hospital, interactive puppet shows, medical demonstrations using dolls and peer-modelling films were effective in reducing children's anxiety during hospitalisation and children's post hospitalisation negative behaviours (Ferguson, 1979; Melamed & Seigel, 1975; Weaver & Groves, 2010; William LI, Lopez, & Lee, 2007; Zahr, 1998).

Other interventions were implemented during hospitalisation. Play therapy and reading groups (on topics such as caregiver-child separation and hospitalisation) were effective in reducing children's anxiety during hospitalisation (Almeida, 1981; Ellerton, Caty, & Ritchie, 1985).

Alternatively, hospital staff focused on the children indirectly by supporting their primary caregivers and/or other health workers. Previous research suggests that involving caregivers in their children's care decreased caregivers' experiences of stress (Justus et al., 2006). Providing caregivers with accommodation in or near the hospital was effective in increasing the overall experiences of caregivers during hospitalisation (Franck, Ferguson, Fryda, & Rubin, 2015). Furthermore, a mindfulness-based stress reduction programme for health workers was also effective in reducing health workers' levels of stress (Shapiro, Astin, Bishop, & Cordova, 2005).

In resource rich contexts, these interventions have been effective in reducing children's, caregivers' and health workers' experiences of distress. In South Africa, there is an urgent need to implement simple, low-cost interventions to improve MDR-TB patients' experiences of hospitalisation. However, it is unclear what type of interventions will be effective in the differently resourced contexts of high TB burden countries like South Africa. Therefore, it is important to work with the community in designing and implementing an intervention that is suitable to the Western Cape. Future researchers should evaluate the effectiveness and feasibility of such an intervention (co-constructed with the community).

5.5 Conclusion

Similar to the UK in the 1950's, children with MDR-TB in the Western Cape experience prolonged separations from their caregivers during hospitalisation. Caregivers and health workers expressed that caregiver-child separation during long-term hospitalisation for MDR-TB treatment was a distressing experience. Additionally, they experienced distress as a result of other components of MDR-TB treatment (namely, the adverse effects of the medication and the administration of the medication). Furthermore, in the context of MDR-TB treatment in the Western Cape, children displayed behavioural and emotional problems such as continuous crying, aggression, hyperactivity and withdrawal. Caregivers and health

workers resorted to behavioural and emotional strategies of deception, threat and prioritisation of biomedical health over psychological health of the children.

Children's, caregivers', and health workers' problems that emerged during MDR-TB treatment most likely result from a complex interplay between precipitating, predisposing and maintaining factors. Components of MDR-TB treatment including caregiver-child separation, long-term hospitalisation and anti-MDR-TB medication likely precipitated the onset of the distress and the problems experienced by children, caregivers and health workers. It appears that poverty and exposure to violence predisposed children to developing behavioural problems and caregivers and health workers to using deception and threat, and to prioritising biomedical health over psychological health. Furthermore, the problems were most likely maintained by children's coping mechanisms, children's persisting behavioural problems and caregivers' continuous use of caregiving strategies that reinforced children's difficult behaviours.

I argue that the behavioural and emotional responses observed in children were adaptive responses by children to cope with the stress of MDR-TB treatment in the context of the Western Cape (Melnyk, 2000). Furthermore, caregivers and health workers used the most effective strategies to manage paediatric illness available to them, especially in a context with constrained resources and little emotional support (Bain & Richards, 2016; Petersen, 2000). However, there is an urgent need to improve the experiences of MDR-TB treatment so that children's behaviours are not adaptive responses to stressful contexts and caregivers' and health workers' most effective caregiving strategies are not coping strategies in conditions of stress.

In high-income contexts, children's, caregivers' and health workers' challenges were addressed through significant improvements to childcare in hospitals. Bowlby and Robertson's early work on the severe effects of maternal deprivation on children's

development led to policy changes in the UK. Consequently, the UK government began to enforce that caregivers stay with their children during hospitalisation (Shields & Mohay, 2001; Smith, 2015). These policy changes significantly decreased the likelihood of children developing behavioural and emotional problems during long-term hospitalisation (Brian & Maclay, 1968; Hawthorne, 1974).

This presents a model for how to improve paediatric MDR-TB treatment in the South African context. However, we need to adapt the model to be appropriate and feasible in the South African context. Future research should design and evaluate the effectiveness and feasibility of such an intervention (co-constructed with the community) in the context of South Africa.

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Appendix A

Information Sheet and Consent Form

	STELLENBOSCH UNIVERSITY **FACULTY OF HEALTH SCIENCES**	

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Exploring caregivers' and health workers' perceptions of children separated from their caregivers during long-term hospitalisation for MDR-TB in the Western Cape: A Qualitative Study

REFERENCE NUMBER: 1710

RESEARCHER: Miss Kyla Meyerson

ADDRESS: Desmond Tutu TB Centre, Department of Paediatrics and Child Health, Clinical Building, Faculty of Health Sciences, Stellenbosch University, Francie van Zijl Drive, Tygerberg, 7505

CONTACT NUMBER: Tel 021 938 9847/6; after hours: 083-661-6764

You or your child are invited to take part in a research study. Please take some time to read the information presented here, which will explain the details of this study. Please ask the study staff or doctor any questions about any part of this study and your child's participation that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you/your child could be involved. Also, your/your child's participation is **entirely voluntary** and you are free to decline to let him/her participate. If you say no, this will not affect you and your child negatively in any way whatsoever. You are also free to withdraw yourself/ your child from the study at any point, even if you do initially agree to let them take par

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

Tuberculosis (TB) is a very important health problem in South Africa. The medicines usually given for TB are the so called "first-line" medicines (drugs): Isoniazid (INH), Rifampicin (RMP) and Pyrazinamide (PZA). These medicines are very good at treating "normal" or drug-susceptible TB. However, if your child has TB that is resistant to at least the two most

important first-line medicines (that is INH and RMP, the “normal” medicines to cure TB), these medications do not work anymore, and this is called multidrug-resistant TB (or MDR-TB). Therefore your child needs to receive medicines that are called “second-line TB drugs” to cure the MDR-TB. In order to receive these “second-line TB drugs” often your child needs to be in hospital for some time. In this study we want to look at the experiences of long-term hospitalisation of children with MDR-TB. We will recruit about 20 to 30 children, parents/caregivers and health workers into the study. We will include children of ages 0 to 5 years.

Why have you been invited to participate?

You and/or your child have been invited to participate in this study because your child has been hospitalised for MDR-TB or because you work on a ward that has paediatric patients with MDR-TB.

Where will this study happen?

This study will be conducted in the Western Cape Province, South Africa. We will recruit children who are being or have been treated for MDR-TB at the Brooklyn Chest Hospital.

What will happen to my child in this study?

If you decide to allow your child to take part in this study, we will ask you or your child some questions. This will take 60-90 minutes. The topics of the questions will include: background information on your child/your patient, your child’s relationship to their caregiver(s) / your patient’s relationships with their caregiver(s) and your child’s experience of hospitalisation and separation from their caregiver(s)/ your patient’s experience of hospitalisation and separation from their caregiver(s).

What will your responsibilities be?

Your responsibilities will be to come to appointments with researcher for the scheduled interviews.

Will you benefit from taking part in this research?

There will be no direct benefit for your child being in this study. Information from this study may however, in future help experts decide better ways to treat children with MDR-TB. This will be important for children treated for MDR-TB in South Africa.

Are there any risks involved in your taking part in this research?

There is minimal risk to you or your child for participating in this study. There is some risk that some of the questions we ask may be uncomfortable and make you feel worried, anxious, sad or embarrassed. If any of these questions make you feel this way, the researcher will go onto the next question or stop the discussion. All researchers are trained to provide support to

you or your child should this occur and are instructed to refer participants to routine psychological support where appropriate.

If you do not agree to take part, what alternatives do you have?

For parents/caregivers or children only:

Should you decide that you do not want to participate in this study or do you want your child to take part in this study; your child's usual medical treatment will not be affected. Your child will continue to receive the usual care for MDR-TB from your routine doctors or clinic.

For health workers only:

Should you decide that you do not want to participate in this study your job will not be affected.

Will anyone know that I am in this study?

The researcher will protect your confidentiality. Confidentiality means we that we will protect your identity and take steps to make sure that your story and other identifying images or records are separated from your identity as a person. We do this so that someone else cannot read one of reports or see our presentation and know that it was your story. We keep confidentiality by not saving the data or recording with your name on it but rather saving it with a unique study number. We also change your name to a fake name when we report on your story. We also store your data in a safe and secure way so only staff can have access to it.

Who will have access to your information?

There are some people who may review the records of your data. They do this to check that we the researchers ae treating you in the correct way and otherwise adhering to the guidelines for good scientific practice. The people who may review your records include: Stellenbosch University Health Research Ethics Committee.

There are some things that if you told us then we would be legally obliged to report this to the relevant authorities. For example, if we observe child abuse, we would need to report this to the Ethics Committee immediately and this matter will be referred to the appropriate services.

Will you be paid to take part in this study and are there any costs involved?

For children only:

You will not be paid to take part in the study.

For parents or caregivers only:

You will not be paid to take part in the study. However, we will reimburse you for your travel costs.

For health workers only:

You will not be paid to take part in the study.

Is there anything else that you should know or do?

You can contact Miss Kyla Meyerson at tel - 083 661 6764 if you have any further queries or encounter any problems or my supervisors, Mark Tomlinson at tel - 021 808 3446 and Graeme Hoddinott at tel - 021 938 9812.

You can contact the Health Research Ethics Committee at tel – 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You will receive a copy of this information and consent form for your own records

CHILD PARTICIPANT

_____ _____

Name Surname

PARENT/LEGAL GUARDIAN

_____ _____ _____

Name Surname Relationship to Child

By signing below, I ……..……. agree for my child to take part in a research study entitled *Exploring caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape: A Qualitative Study.*

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- If you have either read or have heard this information in this Informed Consent Form, if all your questions have been answeed, and if you agree for your or your child/participant to take part in the study, please print and sign your name and write the date.

Parent/Legal Guardian Signature	Thumbprint if parent/guardian illiterate	Date

PARENT/ CAREGIVER or HEALTHCARE WORKER PARTICIPANT

Name	Surname

By signing below, I ……..……. agree to participate in a research study entitled *Exploring caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape: A Qualitative Study*

I declare that:

- ☐ I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- ☐ I have had a chance to ask questions and all my questions have been adequately answered.
- ☐ I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- ☐ I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

If you have either read or have heard this information in this Informed Consent Form, if all your questions have been answeed, and if you agree for your or your child/participant to take part in the study, please print and sign your name and write the date.

Yes	No

_____		
Participant Signature	Thumbprint if participant illiterate	Date

WITNESS IF ILLITERATE

_____	_____	_____
Name	Surname	Signature

Date

PERSON OBTAINING WRITTEN PERMISSION

I *(name)* ……..…… declare that:

- ☐ I explained the information in this document to ……..
- ☐ I encouraged him/her to ask questions and took adequate time to answer them.
- ☐ I am satisfied that he/she adequately understands all aspects of the research, as discussed above

Signed at (*place*) .....….....…….. on (*date*) ……....…….. at (time) ……

Signature of person obtaining written permission

…….

Appendix B

Discussion Guide (Round One)

Purpose: This study aims to explore caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.
Objectives:

1. To explore caregivers' perceptions on caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.
2. To explore health workers' perceptions on caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.

Expected time per use: 60 – 90 minutes in total per discussion
Instructions for use:

- Preamble to be read by the facilitator
- Facilitator to read bolded text and elaborate with prompts below at their discretion
- Facilitator should use the guide flexibly with each participant over the course of several interactions with them

Preamble (**to be read by facilitator**):
Today is the (**insert date [day xxth of xxxx]**) and it is (**insert time XX:XX**). This is a discussion with (**insert participant**) who is a participant in the study 'Exploring caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape: A thematic analysis of qualitative data'. Thank you for giving me the time to talk to you. In this interview, we want to explore caregivers' and health workers' perceptions of caregiver-child separation in the context of long-term hospitalisation for MDR-TB. We are going to record this conversation with this audio recorder so that we can remember our conversation. Please try to talk loudly and clearly in the audio recorder so that we will be able to hear our conversation in the recording. I also might write down some notes during the conversation so that I can remember what we discuss. Do you have any questions before we start?

Topic area 1: Background information of the child

Introduction for the caregiver
In the first part of the discussion, we would like to spend some time learning more about your child.

Introduction for the health worker
In the first part of the discussion, we would like to spend some time learning more about one of your MDR-PK2 patients or MDR-PK2 patients under the age of 5 more generally.

1.1 Descriptions of the child

E.g. question for the caregiver: Please tell me more about your child.

- What is your child's name? How old are they?
- How long have they been in hospital? For how long will they be in hospital? How long were they in hospital?
- What is your child's personality/ temperament like? Does he/she like to socialize/ spend time alone; is he/she outgoing or shy?; is he/she playful or serious?

- What does your child like/dislike to do the most? Drawing/sport/story telling/singing/ dancing/ spending time with friends?
- Does your child have any fears? What are they?
- What makes your child …(angry/sad/happy/excited)?
- How do your child respond to… (anger/sadness/happiness/excitement)?

E.g. question for health worker: Please tell me about this patient/ your patients more generally.

- What is his/her name? How old are they?
- How long have they been in hospital? For how long will they be in hospital?
- What is the child's personality/temperament like? Does he/she like to socialize/ spend time alone; is he/she outgoing or shy?; is he/she playful or serious?
- What makes this child different from other children in the ward?
- What does this child like/dislike to do the most? Drawing/sport/story telling/singing/ dancing/ spending time with friends?
- Does this child have any fears? What are they?
- What makes the child …(angry/happy/sad/excited)?
- How does this chid respond to…(anger/sadness/happiness/excitement)?

1.2 Child's family

E.g. question for the caregiver: Please can you tell me about your child's family?

- Who is in your family? Who is in your extended family?
- Who does your child live with now? / Who did you child live with prior to hospitalisation? Who does your child live with post-hospitalisation?
- Please tell me more about the community that your child is from. How do you feel about the community that your child is from? What do you think of the people that live there? Do you spend much time with other people in the community?
- Which family member does your child like to spend the most time with? Why?
- Please tell me more about your family history. What have been some of the highlights in your family history? What have been some of the low points?

E.g. question for health worker: Please tell me a bit about the patient's family background.

- Who does the child live with?
- Where is the child from? What is the community like that the child is from?
- Who are child's parent/caregivers?
- Who are the child's siblings?
- Who brought the child to the hospital for the first time?
- What does the child like/dislike about their family?
- What are the strengths/ weaknesses of the child's family?
- Please tell me anything else that might be interesting about this family.

1.3 Experiences of MDR-TB

E.g. question for caregiver: Please tell me what it's like for your child to have MDR-TB

- Where in the body does your child feel sick?
- Does your child complain about their body being sore? Where? How often?

- Since being sick, what changes have occurred in the child's behaviour? (e.g. difficulty sleeping, walking etc.)
- How is your child coping?
- How are you and your family coping?
- What are the challenges for your child?
- What are the challenges for you and your family?
- What are the biggest milestones/ successors since your child has been on medication?
- Is there anything the child could not do when they first got here but now can?
- Has the treatment helped restore the child's normal behaviour?
- Does the treatment seem to be helping? Why/why not?
- Who knows that your child is sick? Why or why not?
- How did they react? Do you feel supported by them?
- What were things like at home, at school or in the family before your child got sick? / What were things like at home, at school or in the family after your child got sick?
- What are you and your chid looking forward to the most when he/she is healthy again?

E.g. question for health worker: Please describe some of the experiences of a child with MDR-TB.

- How does the child feel physically?
- Where in the body is the child sore?
- Has the illness led to any behavioural changes? (e.g. sleeping patterns, ability to walk/talk)
- How does the child feel emotionally? How is the child coping with this illness?
- How does the family feel emotionally? How is the family coping with the illness?
- What are the challenges for the child? What are the challenges for the family?
- How is the treatment going for this child?
- What usually happens to a child's body when they take this treatment?
- How are they coping with taking the treatment?
- What are the biggest milestones/ successors since the child has been on treatment?
- Is there anything the child couldn't do when they first got here but now can?
- Has the treatment helped restore the child's normal behaviour?
- What is the chid looking forward to the most when he/she is healthy again?

1.4 Activities during the day:

E.g. question for caregiver: Please tell me about your child's daily activities whilst at hospital.

- What does your child do every day at the hospital?
- Are there daily activities for the children? Probe: school/ play sessions
- What does your child like/dislike about these daily activities?
- What are the daily routines with regard to medication, meals, shower time etc.?
- What does your child like/dislike about these daily routines?
- What do you think is his/her best part of the day?
- What do you think is his/her worst part of the day?

- In what ways is his/her day different now from before being in hospital? In what ways is his/her day different now after being in hospital?

E.g. question for health worker: Please tell me about the daily routine of the patients in this ward.

- Please run me through a day in the life a child with MDR-TB/ MDR-PK2 participant at Brooklyn Chest Hospital.
- Are there any daily activities? What are they? (school, play sessions)
- How does this child respond to the daily activities?
- What are the daily routines with regard to medication, meals, shower time etc.?
- How does this child respond to daily routines (e.g. injections, meals, standing in line for pills)?
- What is the best part of the day for the child?
- What is the worst part of the day for the child?

Topic area 2: Child's relationship to caregiver(s)

Introduction for the caregiver

We want to chat to you about your child's caregiver(s). We also want to know how being in hospital has changed these relationships. We want to know who provides emotional and physical support for your child. We want to know if your child is experiencing different types of support from different caregiver(s). We want to know what roles each caregiver serves in the different environments of the child (home, hospital, school etc.).

Introduction for the health worker

We want to chat to you about the child's/ children's caregiver(s). We also want to know how being in hospital has changed these relationships. We want to know who provides emotional and physical support for the child/ children. We want to know if the child/children is/are experiencing different types of support from different caregiver(s). We want to know what roles each caregiver serves in the different environments of the child/children (home, hospital, school etc.).

2.1 Child's caregivers

E.g. question for the parent/caregiver/caregiver: Please can you tell me about the child's primary caregiver(s).

- I can imagine that caregivers may provide some or all of the following caregiving roles/functions: emotional support, playmate, safety, discipline, provide food and educating the child. Which one(s) would apply to you? What role do these caregiver(s) play for this child?
- What makes /these relationship(s) more special than the child's other relationships?
- Please tell me about any other people who may have cared for your child in the past.
- How have these relationships been affected by hospitalisation?

E.g. question for health worker: Please tell me who about the child's primary caregiver(s).

- What role does this caregiver serve in the child's life?
- Is there someone in particular who the child asks for when he/she is scared or sad?
- What makes this relationship more special than the child's other relationships?
- Please tell me about any other people who may have cared for this child in the past.

- In the Western Cape, who typically serves as the child's primary caregiver(s)?
- Please explain whether the caregiver is the biological parent or someone else.
- How have these relationships been affected by hospitalisation?

2.2 Child's caregiver at home

E.g. question for parent/caregiver: Please tell me about the child's main caregiver at home

- Remember I mentioned that caregivers may have different roles. Which roles does this caregiver fulfil?
- Does this caregiver offer cognitive support/ emotional support/ play with the child / discipline the child?
- What is the child's relationship with this person like?
- Does the child open up emotionally to this person?
- Does this child like to play with this caregiver?
- When do they visit? When do they not visit? Why?
- How do the visits/ lack of visits affect the child's relationship with this caregiver?
- How has this relationship been affected by the child being in hospital?

E.g. question for health worker: Please tell me about the child's main caregiver at home.

- What role does this caregiver serve in the child's life?
- Does this caregiver offer cognitive support/ emotional support/ play with the child / discipline the child?
- What is the child's relationship with this person like?
- Does the child open up emotionally to this person?
- Does this child like to play with this caregiver?
- Does this caregiver serve the role as a disciplinarian for this child?
- When does this caregiver visit? When do they not visit? Why?
- How does the visit/ lack of visits affect this relationship?
- Did this person bring the child to the hospital for the first time/ for the child's admission?
- What observations did you make about the child's relationship with this caregiver from your first interaction with them?
- Who usually brings the children to hospital for admission?
- How has the child's relationship with their main caregiver changed since being in hospital?

2.3. Caregiver(s) and relationships at the hospital

E.g. question for the caregiver: Please tell me about the different relationships your child has at the hospital. I'd like to know about their friendships with other patients and about their relationships with their health workers and the doctors.

- Who looks after your child at hospital?
- Who feeds/baths him/her?
- Who helps him/her when he/she cries/is scared?
- Who offers the child emotional support?

- Who spends the most time with the child at the hospital?
- Who does your child like/ not like to spend time with at the hospital?
- Nurses/ other patients/ doctors?
- Please tell me about any friendships that your child has formed during hospitalisation.
- Please describe the health workers' relationships with your child.
- In what ways is the relationship that the chid has with the health worker similar/ different to the relationship the child has with other caregiver(s).

E.g. question for health worker: Please tell me more about the different relationships that children form at the hospital. I want to know more about children's friendships with other patients and about their relationships with their health workers and the doctors.

- Who looks after the child at hospital?
- Who feeds/baths the children?
- Who helps the children when they cry/are scared?
- Who provides emotional support?
- Who provides cognitive stimulation?
- Who spends the most time with the child?
- Who does the child like spending time with? Who does the child not like spending time with?
- How does the child engage with other children/ health workers at the hospital?
- Please describe health workers relationships with the children. What role does the health worker serve to the child?
- Are health workers at the hospital responsible for one child or many children?
- Do different health workers serve different needs of the children?
- In what ways is the relationship that the chid has with the health worker(s) similar/ different to the relationship(s) that the child has with other caregiver(s)?

Topic area 3: Child's experiences of hospitalisation and separation from their caregiver(s)

Introduction for the caregiver

We want to chat to you about your child's reactions to hospitalisation. We want to know more about what it was like in the beginning and we want to know how your child is managing now. We also want to know more about how you understand or make sense of their reactions.

Introduction for the health worker

We want to chat to you about children's reactions to hospitalisation. We want to know how children respond/cope on the first day, then in the first week, then a month into hospitalisation and then a few months into hospitalisation. We also want to know more about how you understand or make sense of these responses.

3.1 Prior experience with separations

E.g. question for caregiver: Please tell me about times when you have been separated from your child previously

- Have there been times where you were separated from your child previously?
- Why were you separated?

- How long were you separated for?
- Who took care of your child during this time?
- How did your child manage without you during this time?
- Do you think this prior experience has affected how he/she coping with separation now? Please explain your reasoning.

E.g. question for health worker: Please tell me about times when this child has been separated from their caregivers previously

- Have there been times when this child was separated from his/her caregiver previously? Why?
- Do children in the Western Cape typically experience separations from their main caregivers prior to hospitalisation?
- For how long are they usually separated?
- Why are the typical reasons for separation?
- Do you think a child's previous experiences of separation might affect their ability to cope with separation due to long-term hospitalisation for MDR-TB? Please explain.

3.2. Preparation for hospitalisation

E.g. question for parent/caregiver: Please tell me about the first time you heard that your child had to be hospitalised long-term.

- Who told you that your child had to be hospitalised?
- How did you feel when they told you this news?
- What did they tell you about being in hospital?
- How long did they say he/she would stay here?
- What did they say it would be like at the hospital?
- Who told your child that he/she had to be hospitalised?
- How do you think your child felt when they/you told him/her?
- Do you think you and your child were prepared enough for this hospitalisation process? Please explain.
- In what ways could hospital staff in the future better prepare children and their families for long-term hospitalisation?

E.g. question for health worker: Please describe how families typically learn that their child needs to be hospitalised long-term.

- Who told the patient about their admission to hospitalisation?
- What did they tell them? (e.g. length of hospital stay, what will happen during hospitalisation)
- How did the patient and the family respond to this news?
- Do you ever have to tell patients that have they be admitted to hospital long-term?
- What is your approach to telling them this news?
- How do patients and families usually react?
- Is there a systematic process to prepare a child and their family for hospitalisation? Why? Who not?
- If there is not a process: Do you think there should be a process to prepare children and their families for hospitalisation? What would this preparation look like?

3.3 Arrival at hospital

E.g. question for caregiver: Please tell me how your child initially responded to hospitalisation.

- Please give me a break down of what happened when you and your child arrived at the hospital.
- Who dropped your child at the hospital?
- What was the first thing you did when you got to the hospital?
- How did your child respond to his/her arrival at hospital?
- Did he/she ask lots of questions?
- Did he/she look scared?
- How did your child respond to saying goodbye to you?
- Why do you think your child responded in this way?

E.g. question for health worker: Please tell me how the child initially responded to hospitalisation

- Please give me a break down of what happened when the child arrived at the hospital.
- Who dropped the child at the hospital?
- Who welcomed the child at the hospital?
- What happened when their caregiver said goodbye to the child?
- What was their first day at hospital like?
- What was the child's first night at hospital like?
- How do children typically respond to their first day in hospital?
- How do children typically respond to their first night in hospital?

3.4 Responses to hospitalisation

E.g. question for caregiver: Please can you give me a break down of your child's responses to hospitalisation on the first day, the first week, the first month, 6 months in and then post-hospitalisation. I want to know how they responded in terms of their behaviour, their emotions and their relationships.

- How did they respond to the first day of hospitalisation?
- How did they respond in the first week?
- What changed after the first month?
- Please describe if there were any changes after the first six months.
- Please explain your understanding of these changes.
- How is the child now that he/she has been in hospital for some time?
- How has your child's emotional state changed since he/she has been in hospital?
- How has his/her behaviour changed?
- How has his/her relationship with you changed?
- How has his/her personality changed?
- Do you know if there was a time when your child started to settle more in hospital? Please explain this.
- How is your child not that they have been discharged from hospital?

E.g. question for health worker: Please can you give me a break down of the child's responses to hospitalisation in terms of their behaviour, their emotions and their relationships?

- How did the child react to their first night in hospitalisation?
- How did they respond to the first day of hospitalisation?
- How did they respond in the first week?
- Did you notice any changes after the first month?
- Did you notice any changes after he first six months?
- How is the child now that he/she has been in hospital for some time?
- Please explain your understanding of these changes.
- How has your child's emotional state changed since he/she has been in hospital?
- How has his/her behaviour changed?
- How has his/her relationship with you changed?
- How has his/her personality changed?
- Do you know if there was a time when the child started to settle more in hospital? Please explain.
- Are there usually changes in a child's behaviour and personality after being in hospital for some time?
- How do children usually respond to the first week of hospitalisation on the first day?
- Does it seem that children start to settle down after some time in hospital? When does it appear that children have started to settle down in the hospital?
- What changes do parent/caregivers usually report about their children after discharge?

3.5 Child's responses to hospital visits

E.g. question for caregiver: Please tell me what it is like to visit your child.

- How does your child respond to your arrival? Please explain why you think he/she responds in this way.
- How does your child respond to your departure? Please explain why you think he/she responds in this way.
- How do you feel when you arrive to visit your child?
- How do you feel when you leave?

E.g. question for health worker: Please tell me about the child's experience of receiving visitors.

- How does the child respond to the arrival of visitors?
- How does the child respond when the visitors leave?
- How do other child typically respond when visitors arrive/leave?
- Please explain why you think children respond in these ways.

3.6 Child's responses to feeling sick

E.g. question for parent/caregiver: Please tell me what happens when your child is feeling sick.

- How does your child respond to feeling…(sick/pain/upset/angry)?
- Different children use different strategies for coping when they are sick. Some become very needy and clingy and always asking for help. Otherwise are independent

and want to manage by themselves. Which strategy fits your child? Why do you think they are this way? As it always been this way? Please explain why you think they choose this strategy.

- Who or what comforts your child the most when he/she is feeling …(sick/pain/upset/angry)?
- When you or another caregiver or health worker help them do they calm down or stay upset? Please explain why you think this happens.

E.g. question for health worker: Please tell me how the child handles being sick.

- How does child respond to… (pain/feeling sick/discomfort/ sadness/ anger)?
- Does the child/children usually retreat to themselves or do they ask for help? Please explain why you think they choose this strategy.
- What or who comforts the child the most when he/she is feeling sick?
- When a health worker or caregiver helps them do they calm down or stay upset? Please explain why you think they calm down/ stay upset.
- When the child is sore from the injection, what/who usually helps them to feel better?

3.7 Caregiving strategies

E.g. question for parent/caregiver: Please describe your caregiving strategies

- How do you respond to your child when he/she …(cries/shouts/ is sad/ is angry)?
- What strategies do you use to calm your child when they are angry/sad?
- How do you feel when your child …(asks for help/cries/ is angry/ is sad)?
- When you try to help your child, do they usually calm down quickly or does it take them some time to calm down? Please explain why you think the child does this.
- Please give me a break down of what happens when you say goodbye to your child from a visit or when you said goodbye after their hospital admission.
- How did your child respond?
- What do you do/say to your child?
- Did this help your child?

E.g. question for health worker: Please describe your and other health workers' strategies of caring for the children on the ward.

- What do you think will help the child the most when they feel pain, sick, angry or frustrated?
- How do you and other health workers typically respond to an emotional child whose parent has just left from a visit? Why do you choose this sort of response?
- What are your strategies for helping a child who is upset/sore from his/her injection? Why do you choose this strategy?
- When you try to help the child, do they usually calm down quickly or does it take them some time to calm down? Please explain why you think the child responds in this way.
- How does the child's caregiver from home respond to the child when they say goodbye from a visit? Why do you think the caregiver responds in this way?

Appendix C

Discussion Guide (Round Two) – Caregivers

Discussion Guide

Purpose: This study aims to explore caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.
Objectives:

1. To explore caregivers' perceptions on caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.
2. To explore health workers' perceptions on caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.

Expected time per use: 60 – 90 minutes in total per discussion
Instructions for use:

- Preamble to be read by the facilitator
- Facilitator to read bolded text and elaborate with prompts below at their discretion
- Facilitator should use the guide flexibly with each participant over the course of several interactions with them

Preamble (**to be read by facilitator**): Today is the (**insert date [day xxth of xxxx]**) and it is (**insert time XX:XX**). This is a discussion with (**insert participant**) who is a participant in the study 'Exploring caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape: A thematic analysis of qualitative data'. Thank you for giving me the time to talk to you.

Introduction

- This study is part of a larger study that looks at medicines for MDR-TB. But in this study we want to explore caregiver-child separation. We want to know what it was like for you and your child to be separated from each other when your child was in hospital. We want to know how your child responded to hospitalisation.
- We will be using an audio recorder.
    - To remember conversation
    - Please talk loudly and clearly
    - Nobody else will have access to recording except study team
- Do you have any questions before we start?

Topic area 1: Background information of the child

Introduction for the caregiver

Before we start talking to you about separation. We want to know more about your child, your family and your background.

1.1 Descriptions of the child

E.g. question for the caregiver: Please tell me more about your child.

- What is your child's name? How old are they?

- How long have they been in hospital? For how long will they be in hospital? How long were they in hospital?
- What is your child's personality/ temperament like? Does he/she like to socialize/ spend time alone; is he/she outgoing or shy?; is he/she playful or serious?
    - If parent does not know: ask if they have thought about this before.
    - Was child similar or different from your other children/ other children in your community.
    - If caregiver says child was easy, then ask: If he/she was like this as a baby? Not a lot of babies are like that, you are lucky. Was he/she similar/different from your other children. What do you think contributed to this?
- What does your child like to do for fun or not like to do? Drawing/sport/story telling/singing/ dancing/ spending time with friends?
- Does your child have any fears? What are they?
- What makes your child …(angry/sad/happy/excited)?
- How do your child respond to… (anger/sadness/happiness/excitement)?

1.2 Child's family

E.g. question for the caregiver: Please can you tell me about your child's family?

- Who is in your family? Who are you staying with?
- Who does your child live with now? / Who did you child live with prior to hospitalisation? Who does your child live with post-hospitalisation?
- Please tell me more about the community that your child is from. How do you feel about the community that your child is from? What do you think of the people that live there? Do you spend much time with other people in the community?
- Please tell me more about your family history. What have been some of the good times in your family history? What have been some of the bad times?

1.3 Child's responses to feeling sick

E.g. question for parent/caregiver: Please tell me a story about your child being sick in the past. How did he/she respond?

- How does your child respond to feeling…(sick/pain/upset/angry)?
- Different children use different strategies for coping when they are sick. Some become very needy and clingy and always asking for help. Others are independent and want to manage by themselves. Which strategy fits your child? Why do you think they are this way? Has it always been this way? Please explain why you think they choose this strategy.
- Who or what comforts your child the most when he/she is feeling …(sick/pain/upset/angry)?
- When you or another caregiver or health worker help them do they calm down or stay upset? Please explain why you think this happens.

Topic area 2: Child's experiences of hospitalisation and separation from their caregiver(s)

Introduction for the caregiver

We want to chat to you about:
-what it was like for you
-what is was like for your child
-how your child reacted a) emotionally b) behaviourally c) your relationships

2.1 Experiences of caregiver-child separation.

E.g. question for caregiver: Please tell me how it was to be separated from your child

- What was it like for you?
- What was it like for your child?

2.2 Timeline.

E.g. question for caregiver: Please can you give me a break down of your child's responses to hospitalisation on the first day, the first week, the first month, 6 months in and then post-hospitalisation. I want to know how they responded in terms of their behaviour, their emotions and their relationships. We are going to use a timeline so it will be easier to follow all the events.

- Examples of some useful probes:
  - What was it like?
  - Can you give me an example/ story of what happened then?
  - How did you feel? Why?
  - How did your child feel? Why?
  - How did your child responded? Why?
  - Why do you think your child responded like this?
  - Why do you think this response was different from his/her previous response?

1. Finding out that you had MDR-TB.

- How did you find out that your child was sick? How did you feel? How did your child feel?
- Where in the body does your child feel sick?
- Does your child complain about their body being sore? Where? How often?
- Since being sick, what changes have occurred in the child's behaviour? (e.g. difficulty sleeping, walking etc.)
- How is your child coping?
- How are you and your family coping?
- What are the biggest milestones/ successes since your child has been on medication?
- Is there anything the child could not do when they first got here but now can?
- Has the treatment helped restore the child's normal behaviour?
- Does the treatment seem to be helping? Why/why not?

- What are you and your chid looking forward to the most when he/she is healthy again?

2. Admission to Tygerberg

- Who stayed with your child?
- Did your child's behaviour or emotions change during this time?

3. Finding out that your child has to be in hospital long-term

- Who told you that your child had to be hospitalised?
- How did you feel when they told you this news?
- What did they tell you about being in hospital? How long did they say he/she would stay here? What did they say it would be like at the hospital?
- Who told your child that he/she had to be hospitalised?
- How did he/she respond?
- Did you notice any changes in his/her behaviour?

4. Arrival at hospital

- Please give me a break down of what happened when you and your child arrived at the hospital.
- Who dropped your child at the hospital?
- What was the first thing you did when you got to the hospital?
- How did your child respond to his/her arrival at hospital? Did he/she ask lots of questions? Did he/she look scared?
- How did your child respond to saying goodbye to you?
- Why do you think your child responded in this way?

5. First night at hospital

- How do you think your child reacted on the first night?
- What do you think he/she was thinking?

6. First week at hospital

- How did they respond in the first week?
- Do you think that there were any changes in his/her behaviour/emotions since the first day?

7. Visit during first week/ going home for a weakened during first week

- When was the first time you visited? How does your child respond to your arrival? Please explain why you think he/she responds in this way.
- How does your child respond to your departure? Please explain why you think he/she responds in this way.
- How do you feel when you arrive to visit your child?
- How do you feel when you leave?

- How did your child respond when he/she came home for a weekend?

8. First month at hospital

- What changed after the first month?
- Was there a difference in his/her behaviour/emotions since the first few?
- Do you think that there have been any changes in his relationship with you since he has been in hospital?
- Do you think that your child settled/ got used to being in hospital?

9. Visit during first month/ going home for a weakened during first month

- Was the visit in the first month different from her visits in the first week? Why?
- Did you notice any changes?
- How does your child respond to your arrival? Please explain why you think he/she responds in this way.
- How does your child respond to your departure? Please explain why you think he/she responds in this way.
- How do you feel when you arrive to visit your child?
- How do you feel when you leave?
- How did your child behave when he/she came home for a visit? Was this different from the first time he/she came home?

10. Few months in hospital

- Please describe if there were any changes in his/her behaviour or emotions after the first six months. Please explain your understanding of these changes.
- How is the child now that he/she has been in hospital for some time?
- How has your child's emotional state changed since he/she has been in hospital?
- How has his/her behaviour changed?
- How has his/her relationship with you changed?
- How has his/her personality changed?
- Do you know if there was a time when your child started to settle more in hospital? Please explain this.

11. Hospital visits during first few months/ going home for a weakened during first month

- How did your child respond when you visited him/her after a few months?
- Was this different from the first month?
- What did your child do when you arrived?
- What did your child do when you left? Was this different from previous visits?
- How did your child behave when he/she came home for a visit? Was this different from previous weekend trip homes?

12. Leaving hospital and arrival home

- Who told you that your child could go home?
- What did your child do when you got home?
- How is your child not that they have been discharged from hospital?
- What was the first day at home like?
- How did your child behave when you got home?

13. First week at home

- Can you tell us a story of anything interesting that happened in the first week?
- Did you notice any changes in his/her behaviour from before hospital?
- Did you notice any changes in his/her emotional responses?
- How did he/she behave with his/her friends?
- How was he/she behaving towards you? Do you think your relationship with him/her changed?

14. First month at home

- Was your child's behaviour different in the first month after being home? Was it different from when you just got home? Why?

15. Three/ four months into being home

- Was your child's behaviour different after a few months? Was it different from the first month? Why?

2.3 Activities during the day:

E.g. question for caregiver: Please tell me about your child's daily activities whilst at hospital.

- What does your child do every day at the hospital? Are there daily activities for the children? Probe: school/ play sessions
- What does your child like/dislike about these daily activities?
- What are the daily routines with regard to medication, meals, shower time etc.?
- What does your child like/dislike about these daily routines?
- What do you think is his/her best part of the day?
- What do you think is his/her worst part of the day?
- In what ways is his/her day different now from before being in hospital? In what ways is his/her day different now after being in hospital?

2.4 Prior experience with separations and spending time with strangers

E.g. question for caregiver: Please tell me about times when you have been separated from your child previously

- Have there been times where you were separated from your child previously?
- Why were you separated?
- How long were you separated for?
- Who took care of your child during this time?

- How did your child manage without you during this time?
- Do you think this prior experience has affected how he/she coping with separation now? Please explain your reasoning.
- Have there been times when your child spent time with strangers/ non-primary caregivers?
- How do you think that your child responded to this?
- Do you think this prepared your child for spending time in hospital with health workers (people that he/she did not know)?

2.5 Preparation for hospitalisation

E.g. question for parent/caregiver: Please tell me if you feel that you were prepared for hospitalisation

- Do you think you and your child were prepared enough for this hospitalisation process? Please explain.
- Do you feel like you were emotionally ready?
- In what ways could hospital staff in the future better prepare children and their families for long-term hospitalisation?

Topic area 3: Child's relationship to caregiver(s)

Introduction for the caregiver

We want to chat to you about your child's caregiver(s). We also want to know how being in hospital has changed these relationships. We want to know who provides emotional and physical support for your child. We want to know if your child is experiencing different types of support from different caregiver(s). We want to know what roles each caregiver serves in the different environments of the child (home, hospital, school etc.).

3.1 Child's caregivers

E.g. question for the parent/caregiver/caregiver: Please can you tell me about the child's primary caregiver(s).

- Please tell me about any other people who may have cared for your child in the past.
- Who would you say is the main caregiver.
- Caregivers can provide many roles to their children. Let's make a list together of the roles you play.
- Probes: emotional support, playmate, safety, discipline, provide food and educating the child. Which one(s) would apply to you? What role do these caregiver(s) play for this child?
- What makes /these relationship(s) different from the child's other relationships?
- How have these relationships been affected by hospitalisation?
- When do they visit? When do they not visit? Why?
- How do the visits/ lack of visits affect the child's relationship with this caregiver?
- How has this relationship been affected by the child being in hospital?

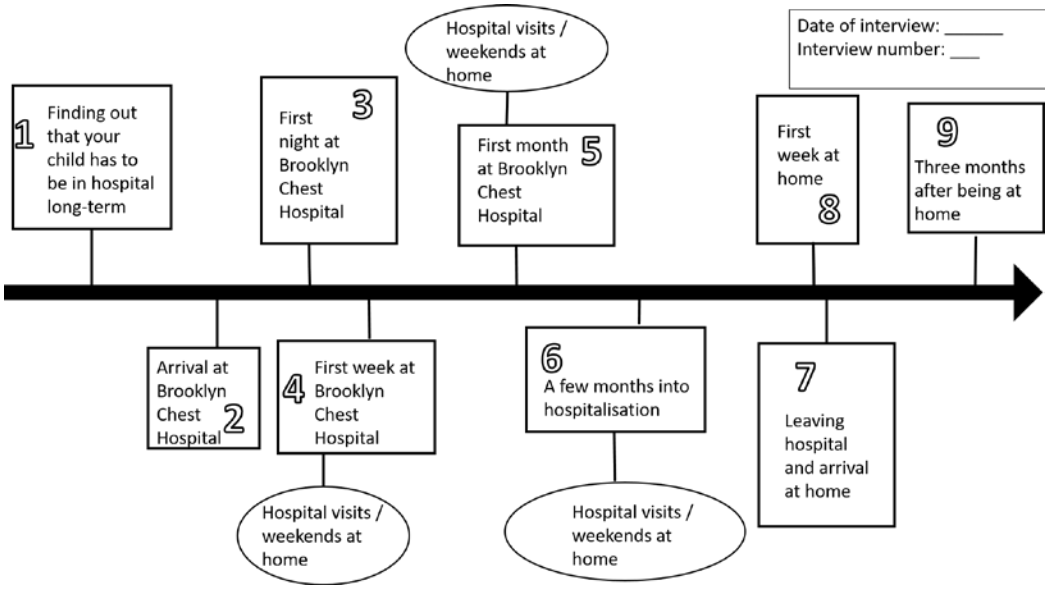
3.2.Child's caregiver(s) at the hospital and other relationship(s) at the hospital

E.g. question for the caregiver: Please tell me about the different relationships your child has at the hospital. I'd like to know about their friendships with other patients and about their relationships with their health workers and the doctors.

- Who looks after your child at hospital? Who feeds/baths him/her? Who helps him/her when he/she cries/is scared? Who offers the child emotional support?
- Who spends the most time with the child at the hospital?
- Please describe the health workers' relationships with your child.
- In what ways is the relationship that the chid has with the health worker similar/ different to the relationship the child has with other caregiver(s).
- Please tell me about any friendships that your child has formed during hospitalisation.
- Were there any other relationships that the child formed in the hospital?
- Do you think any of these relationships helped the child during hospital? why? Why not? In what ways?

3.3.Caregiving strategies

- **E.g. question for parent/caregiver: Please describe your caregiving strategies**
  - How do you respond to your child when he/she …(cries/shouts/ is sad/ is angry)?
  - What strategies do you use to calm your child when they are angry/sad?
  - How do you feel when your child …(asks for help/cries/ is angry/ is sad)?
  - When you try to help your child, do they usually calm down quickly or does it take them some time to calm down? Please explain why you think the child does this.
  - Please give me a break down of what happens when you say goodbye to your child from a visit or when you said goodbye after their hospital admission. How did your child respond? What do you do/say to your child? Did this help your child?



Appendix D

Discussion Guide (Round Two) – Health Workers

Discussion Guide

Purpose: This study aims to explore caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape.
Objectives:

1. To explore caregivers' perceptions on caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.
2. To explore health workers' perceptions on caregiver-child separation in the context of long-term hospitalisation of children with MDR-TB.

Expected time per use: 60 – 90 minutes in total per discussion
Instructions for use:

- Preamble to be read by the facilitator
- Facilitator to read bolded text and elaborate with prompts below at their discretion
- Facilitator should use the guide flexibly with each participant over the course of several interactions with them

Preamble (**to be read by facilitator**): Today is the (**insert date [day xxth of xxxx]**) and it is (**insert time XX:XX**). This is a discussion with (**insert participant**) who is a participant in the study 'Exploring caregivers' and health workers' perceptions of caregiver-child separation during long-term hospitalisation for MDR-TB in the Western Cape: A thematic analysis of qualitative data'. Thank you for giving me the time to talk to you.

In this interview, we want to explore caregivers' and health workers' perceptions of caregiver-child separation in the context of long-term hospitalisation for MDR-TB. We are going to record this conversation with this audio recorder so that we can remember our conversation. Please try to talk loudly and clearly in the audio recorder so that we will be able to hear our conversation in the recording. I also might write down some notes during the conversation so that I can remember what we discuss. Do you have any questions before we start?

Topic area 1: Background information of the child

Introduction for the health worker

In the first part of the discussion, we would like to spend some time learning more about the MDR-PK2 patients under the age of 5 more generally. You can answer in terms of the children more generally or you can answer about the children who are currently in hospital.

1.1 Descriptions of the child

E.g. question for health worker: Please tell me about the current MDR-PK II participants under the age of 5 (more generally).

- What are their names? How old are they?
- How long have they been in hospital? For how long will they be in hospital?

- Do you know them personally? How often do you inteact with them?
- What are their personalities/temperaments like? Does he/she like to socialize/ spend time alone; is he/she outgoing or shy?; is he/she playful or serious?What makes these child different from other children in the ward?
- What do these child like/dislike to do the most? Drawing/sport/story telling/singing/ dancing/ spending time with friends?
- Do these children have any fears? What are they?
- What makes these children …(angry/happy/sad/excited)?
- How do these chidren respond to…(anger/sadness/happiness/excitement)?

1.2 Child's family

E.g. question for health worker: Please tell me a bit about the patient's family background.

- What are the children's family backgrounds like?
- Who does the child live with?
- Where are the child from? What are the communities like that the children are from?
- Who are child's parent/caregivers?
- Who are the child's siblings?
- What are the strengths/ weaknesses of the child's family?
- Please tell me anything else that might be interesting about this family.

Topic area 2: Child's experiences of hospitalisation and separation from their caregiver(s)

Introduction for the health worker

We want to chat to you about children's reactions to hospitalisation. We want to know how children respond/cope on the first day, then in the first week, then a month into hospitalisation and then a few months into hospitalisation. We also want to know more about how you understand or make sense of these responses.

1.1 Caregiver-child separation.

<u>E.g. question for health worker</u>: Please tell me what you think about caregiver-child separation during long-term hospitalisation for MDR-TB.

- What is the first thing that comes to your mind when you think about caregiver-child separation?
- What do you think it is like for the children and their families?

1.2 Timeline

E.g. question for health worker:. Please can you give me a break down of the childen's responses to hospitalisation on the first day, the first week, the first month, 6 months in and then post-hospitalisation. I want to know how they responded in terms of their behaviour, their emotions and their relationships. We are going to use a timeline so it will be easier to follow all the events.

1. Finding out that you had MDR-TB.

- How do the children usually find out that they are sick?
- How did you think the family feels when they find out?
- How did you think the child feels?

2. Admission to Tygerberg

- Who usually stays with the child at TCH?
- How do you think the child and their family usually handles being in TCH?

3. Finding out that your child has to be in hospital long-term

- Who tells the child and their family that the child had to be in hospital?
- Who do you think usually tells the child that they have to be in hospital? How do you think he/she respond? How do you think the child and their family feel when they are told this news?
- What do you think they tell the child and their family about being in hospital?
- How long do you think they say he/she would stay at BCH?
- What do you think they say it would be like at the hospital?

4. Arrival at hospital

- Please give me a break down of what happens when the child and their family arrive at the hospital.
- Who drops the child at the hospital?
- What is the first thing that they do when you got to the hospital?
- How does the child respond to his/her arrival at hospital? Does the child usually ask lots of questions? Does he/she look scared?
- How does the child usually respond to saying goodbye to their parents? Why do you think the child usually responds this way?

5. First night at hospital

- Please can you explain how the child reacts/ responds on the first night?
- Why do you think he/she responds this way?

6. First week at hospital

- How does the child respond in the first week?
- Do you think that there were any changes in their behaviour/emotions since the first day?

7. Visit during first week/ going home for a weakened during first week

- When is usually the first time the parents visit?
- How does the child usuually respond to their arrival? Please explain why you think he/she responds in this way.
- How does the child respond to their departure? Please explain why you think he/she responds in this way.

- How do children respond when they are going home for a weekend?
- How do the children usually respond when they get back from a weekend visit?

8. First month at hospital

- What usually changes in the child's behavior after the first month in hospital?
- Was there a difference in his/her behaviour/emotions since the first few days?
- Do you think that there have been any changes in his/her relationship with their caregiver since he/she has been in hospital?
- Do you think that the child settled/ got used to being in hospital during this time?

9. Visit during first month/ going home for a weakened during first month

- Was the visit in the first month different from their visits in the first week? Why?
- Did you notice any changes?
- How does the child respond to their parents arrival? Please explain why you think he/she responds in this way.
- How does your child respond to their parents' departure? Please explain why you think he/she responds in this way.
- How did the child behave when he/she knew that he/she was going home for a visit during this time period? Was this different from the first time he/she came home?

10. Few months in hospital

- Please describe if there were any changes in his/her behaviour or emotions from first month to a few months later. Please explain your understanding of these changes.
- How is the child now that he/she has been in hospital for some time?
- How has your child's emotional state changed since he/she has been in hospital?
- How has his/her behaviour changed?
- How has his/her relationship with you changed?
- How has his/her personality changed?
- Do you know if there was a time when your child started to settle more in hospital? Please explain this.

11. Hospital visits during first few months/ going home for a weakened during first month

- How did your child respond when their parents visited him/her after a few months?
- Was this different from the first month?
- What did the child do when they arrived?
- What did the child do when they left? Was this different from previous visits?
- How did the child behave when he/she went home for a visit? Was this different from previous weekend trip homes?

- How did the child behave when he/she got home for a visit? Was this different from previous weekend trip homes?

12. Being discharged from hospital

- Who tells the child that they are going home?
- How is your child not that they have been discharged from hospital?
- Who usually fetches the child?
- How do children usually behave in the build up to being discharged from hospital?
- Do you see children in follow up appointments after being discharged?
- Do you see any changes in their behaviour/ emotions?
- Have you heard stories from parents about how children behave after being discharged from hospital?

2.3 Activities during the day during hospital

E.g. question for health worker: Please tell me about the daily routine of the patients in this ward.

- Please run me through a day in the life a child with MDR-TB/ MDR-PK2 participant at Brooklyn Chest Hospital.
- Are there any daily activities? What are they? (school, play sessions)
- How does this child respond to the daily activities?
- What are the daily routines with regard to medication, meals, shower time etc.?
- How does this child respond to daily routines (e.g. injections, meals, standing in line for pills)?
- What is the best part of the day for the child?
- What is the worst part of the day for the child?

2.4 Child's responses to feeling sick

E.g. question for health worker: Please tell me how the child handles being sick.

- How do these children respond to…(pain/feeling sick/discomfort/ sadness/ anger)? Do the children usually retreat to themselves or do they ask for help? Please explain why you think they choose this strategy.
- What or who comforts the child the most when they are feeling sick?
- When a health worker or caregiver helps them do they calm down or stay upset? Please explain why you think they calm down/ stay upset.
- When the child is sore from the injection, what/who usually helps them to feel better?

2.5 Experiences of MDR-TB

E.g. question for health worker: Please describe some of the experiences of a child with MDR-TB.

- How does the child feel physically? Where in the body is the child sore?

- Has the illness led to any behavioural changes? (e.g. sleeping patterns, ability to walk/talk)
- How does the child feel emotionally? How is the child coping with this illness?
- How does the family feel emotionally? How is the family coping with the illness?
- What are the challenges for the child? What are the challenges for the family?
- How is the treatment going for this child?
- What usually happens to a child's body when they take this treatment?
- How are they coping with taking the treatment?
- What are the biggest milestones/ successors since the child has been on treatment?
- Is there anything the child couldn't do when they first got here but now can?
- Has the treatment helped restore the child's normal behaviour?
- What is the chid looking forward to the most when he/she is healthy again?

2.6 Prior experience with separations

E.g. question for health worker: Please tell me about times when this child has been separated from their caregivers previously

- Do children in the Western Cape typically experience separations from their main caregivers prior to hospitalisation? For how long are they usually separated? Why are the typical reasons for separation?
- Do you think a child's previous experiences of separation might affect their ability to cope with separation due to long-term hospitalisation for MDR-TB? Please explain.

2.6 Preparation for hospitalisation

E.g. question for health worker: Please describe how families typically learn that their child needs to be hospitalised long-term.

- Is there a systematic process to prepare a child and their family for hospitalisation? Why? Who not?
- If there is not a process: Do you think there should be a process to prepare children and their families for hospitalisation? What would this preparation look like?
- Do you think parents and children are emotionally prepared for hospitalisation/separation process. Is there a way do you think that they can be better prepared?

Topic area 3: Child's relationship to caregiver(s)

Introduction for the health worker

We want to chat to you about the child's/ children's caregiver(s). We also want to know how being in hospital has changed these relationships. We want to know who provides emotional and physical support for the child/ children. We want to know if the child/children is/are experiencing different types of support from different caregiver(s). We want to know what roles each caregiver serves in the different environments of the child/children (home, hospital, school etc.).

3.1. Child's caregivers

E.g. question for health worker: Please tell me who about the child's primary caregiver(s).

- In the Western Cape, who typically serves as the child's primary caregiver(s)? Please explain whether the caregiver is the biological parent or someone else.
- What role does this caregiver serve in the child's life? Let's make a list.
- What makes this relationship different from the child's other relationships?
- How have these relationships been affected by hospitalisation?
- During hospitalisation, is there someone in particular who the child asks for when he/she is scared or sad?

3.2. Child's caregiver(s) at the hospital and other relationship(s) at the hospital

E.g. question for health worker: **Please tell me more about the different relationships that children form at the hospital. I want to know more about children's friendships with other patients and about their relationships with their health workers and the doctors.**

- Please describe health workers relationships with the children. What role does the health worker serve to the child? Let's make a list.
- Who looks after the child at hospital? Who feeds/baths the children? Who helps the children when they cry/are scared?
- Who provides emotional support?
- Who provides cognitive stimulation?
- Who spends the most time with the child?
- Are health workers at the hospital responsible for one child or many children?
- Do different health workers serve different needs of the children?
- In what ways is the relationship that the child has with the health worker(s) similar/ different to the relationship(s) that the child has with other caregiver(s)?
- In hospital, who does the child like spending time with? Who does the child not like spending time with?
- How does the child engage with other children at the hospital?
- Please describe some of the types of relatonships that children form with their peers during hospital.
- Do you think these relationships influence how the child manages being in hospital?
- Please describe any other types of relationships that children form during hospital. Other health wokers? Doctors? Teacher? Etc.Do you think these relationships influence how the child manages being in hospital?

3.3. Caregiving strategies

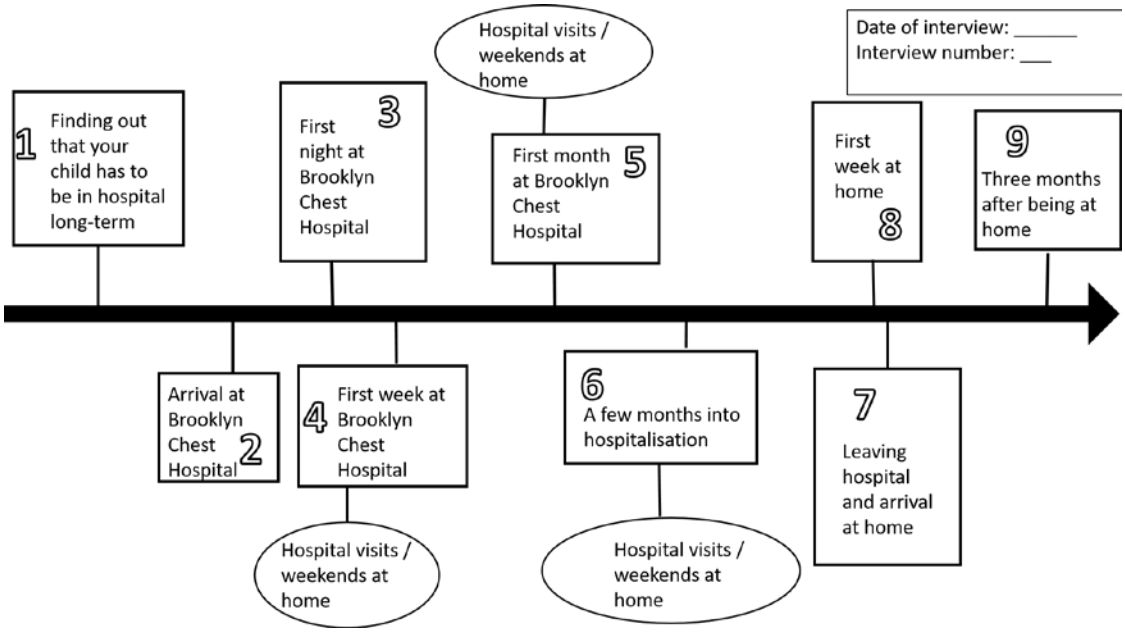
E.g. question for health worker: Please describe your and other health workers' strategies of caring for the children on the ward.

- What do you think will help the child the most when they feel pain, sick, angry or frustrated?

- How do you and other health workers typically respond to an emotional child whose parent has just left from a visit? Why do you choose this sort of response?
- What are your strategies for helping a child who is upset/sore from his/her injection? Why do you choose this strategy?
- When you try to help the child, do they usually calm down quickly or does it take them some time to calm down? Please explain why you think the child responds in this way.

3.4. Final questions and thank you

- Do you think your opinion has changed now that you have thought about this more?
- Do you have any questions?
- Thank you ☺



Appendix E

Transcription Protocol

7. Transcription Symbols

Transcription[1]	Symbols	Short Description
Phrase		
word	SPACE	Space between words
Pause		
pause, timed	(1.2)	Silences and pauses timed
pause, short	..	Silence too short to time
latching	=	Speaker is interrupted
Participation		
participant/turn attribution	S20_W03/S20_M03	Participant identification
Researcher/interviewer		
unidentified speaker	#;	
uncertain speaker	#S20_W03	
Other Identifiers	+word+	
Sequence		
overlap (single)	[ ]	
overlap (2nd)	[₂]	
Dis fluency		
truncated/cut-off word	wor-	
Vocalism		
breathe (in)	(H)	
exhale	(Hx)	
vocalism	(SNIFF)/(COUGH)	
click	(TSK)	
laugh pulse	@	
laughing word	wo@rd	
glottal stop, creak	(%)	
glottalized word	w%ord	
Manner and Quality		
manner/long feature	<words>	
Manner/short feature	>words<	
piano, attenuated speech	°words°	ALT+0176 for °
forte	^words^	
smile quality	☺word	:) for ☺
Inaudible		
unintelligible	###	
uncertain	#word	
comment/notes	((words))	
Boundary/Closure		
terminative	.	
continuative	,	
appeal (final)	?.	
appeal (continuing)	?,	

7.1. Recording Phrases and Pauses

Phrases	
word	SPACE
Pause	
pause, timed	(1.2)

[1] Du Bois: Comparison of Transcription Symbols.
Available: http://www.linguistics.ucsb.edu/projects/transcription/A04comparison.pdf

Appendix F

Extract from a Transcription

R35 @ (1.0) uhm okay☺ so uhm what makes her like.. uhm (1.0) happy?.. or excited?.

S99_W01 .. (1.0) @ @ ☺I don't know

R35 and and unhappy?, .. or what makes what what makes her angry?, is there anything that angers her?.

S99_W01 (H) @ I don't@know

R35 maybe her brothers when they tease her or something

S99_W01 yes (1.0) there will be times when she just fights with them

R35 ^(H)aah^ ((shock)) haai

S99_W01 yes the middle one he's quick to- he for her ((perhaps she means he hits her))

R35 such a wild [woman jong]

S99_W01 [she she #hits the middle one

R35 @@

S99_W01 she hits the middle one ((birds can be heard gwaking))

R35 okay so uhm how does she react when uhm .. uh she is happy like how does she react what does she do whe-- e that you know that she is happy

S99_W01 she gives me hugs she askes me for kisses she tells my love you mommy

R33 ooh that's ### ((voice fades))

Appendix G

Audit Trail

Preliminary Analysis

Theme 1: Short-term responses					
1.1 Protest	**1.2 Despair**	**1.3 Child settles**	**1.4 Confused and mixed reactions to hospital visits**	**1.5 Caregiver-child separation is difficult for the child**	**1.6 Caregiver-child separation is difficult for the caregiver**
1.1.1 Children pleaded for parents not to leave hospital	1.2.1 After a month at BCH, children were withdrawn	1.3.1 After a week in hospital children appeared to have settled	1.4.1. When caregivers visited, children were happy	1.5.1 Caregiver-child separation affected the child negatively	1.6.1 Caregivers missed their children
1.1.2 Children tried to escape from their cots	1.2.2 When parents left from a visit children became quiet	1.3.2 After some time in hospital children still cried and were not settled	1.4.2 When caregivers visited, children cried	1.5.2 Children did not want to be separated from their caregivers	1.6.2 Caregivers did not feel like it was normal to be away from their children
1.1.3 Children felt like they had been dumped in the hospital		1.3.3 After some time in hospital children were happy and felt safe	1.4.3 When caregivers visited, children were clingy	1.5.3 Children felt lonely	1.6.3 Caregivers do not want to be separated from their children
1.1.4 Children were clingy		1.3.4 Children didn't get used to being in hospital	1.4.4 When caregivers visited, children were angry		1.6.4 Caregivers would rather children were treated from home than in hospital
1.1.5 Children asked health workers when caregivers were coming to the hospital		1.3.5 Children got used to being in hospital without their caregivers	1.4.5 When caregivers visited, children were not angry		1.6.5 Caregivers were relieved that their children would be physically healthy
		1.3.6 Children accepted their situation	1.4.6 When caregivers visited, after connecting children calmed down		
			1.4.7 When caregivers left from a visit, children were angry		
			1.4.8 When caregivers left from a visit, children ran after caregivers		
			1.4.9 When caregivers left from a visit, children cried and then calmed down		

Theme 2: Long-term responses		Theme 3: Supportive relationships in the hospital			
2.1 Long-term behavioural and emotional responses	**2.2 Problems are transient**	**3.1 Health workers offer caregiving support to children**	**3.2 Children have different relationships with health workers and caregivers**	**3.3 Supportive friendships with peers in hospital**	**3.4 Other supportive relationships in the hospital**
2.1.1 Children cried continuously	2.2.1 Behaviour restored after three days	3.1.1 Children got attached to health workers	3.4.1 Few health workers attended to many children	3.2.1 Children made friends in the hospital	3.3.1 Child formed a consistent and close relationship with the teacher
2.1.2 Children were clingy	2.2.2 Behaviour restored after a few months	3.1.2 Health workers were available to attend to child's needs	3.4.2 Health workers did not care for children like a parent would have cared for their child	3.2.2 Older children offered support to younger children	
2.1.3 Children were afraid of being left at the hospital again		3.1.3 Health workers got to know child on a personal basis	3.4.3 Health workers did not give personal affection to the children		
2.1.4 Child were playful but had angry moments		3.1.4 Health workers calmed children down when caregivers left	3.4.4 Health workers were not consistently available for the children		

Theme 4: Miscellaneous	
4.1 Caregivers can't visit regularly	**4.2. Miscellaneous**
4.1.1 Financial	4.2.1 Health worker justify caregiver-child separation
4.1.2 Work	4.2.2 Children did not complain about being in hospital
4.1.3 Live far	
4.1.4 Caregiver has MDR-TB	

Final analysis

Theme 1: Experiences of distress		**Theme 2: Children's behaviour and emotional states**			
1.1 Distress from MDR-TB medication	**1.2 Distress from caregiver-child separation**	**2.1 Excessive crying**	**2.2. Anger and aggression**	**2.3. Hyperactivity**	**2.4 Withdrawn behaviours**
1.1.1 Adverse effects of medication (nausea, discoloured skin, numbness & hearing loss)	1.2.1 Families were distressed about separation	2.1.1 Arrival at BCH, children cred and looked for their mother	2.2.1 Children hit	2.3.1 After a few months in hospital children were more hyperactive/ active	2.4.1 Arrival at BCH, children were quiet
1.1.2 Administrating MDR-TB medication was distressing	1.2.2 Children were distressed to be away from their caregivers	2.1.2 First night, children cry and were lonely	2.2.2 Children bit	2.3.2 Children couldn't concentrate at school	2.4.2 Children isolated themselves at BCH
	1.2.3 Health workers were drained from working with children and caregivers who were distressed.	2.1.3 First week children cried	2.2.3 Children swore	2.3.3 On weekend visits at home, children were hyperactive	2.4.3 Children were quiet
		2.1.3 Children cried when caregivers visit	2.2.4 Children were angry with their caregivers		2.4.3 Children withdrew when they missed their caregivers
		2.1.4 After a few months, children cried all the time	2.2.3 After discharge, children were aggressive		
		2.15 After discharge, children cried all the time			
		2.1.6 After some time, children stopped crying			
		2.1.7 After a few months, children were happy and playful			

Theme 3: Caregivers' and health workers' behavioural and emotional management strategies		
3.1 Deception	**3.2 Threat**	**3.3 Prioritisation of biomedical over psychological**
3.1.1 Caregivers deceived children when they left from a visit	3.2.1 Caregivers and health workers shouted and threatened their children	3.4.1 Caregivers had mixed feelings about separation
3.1.2 Caregivers did not explain separation or hospitalisation to their children	3.2.2 Caregivers and health workers labelled children's behaviour as naughty	3.4.2 Health workers were concerned about caregivers' adhering to the medication
3.1.3 Health workers deceived parents	3.3.3 Health workers threatened caregivers to ensure that they adhered to the medication	3.4.7 Preparation for hospitalisation was more biomedical than psychological
3.1.4 Heath workers encouraged parents to deceive children		3.4.1. Caregivers and health workers had a heightened awareness of children's physical health
		3.4.6 Health workers monitored physical aspects more than psychological aspects of children's health
		3.4.7 Caregivers did not want to admit that there were negative behaviour or emotional changes
		3.4.8 Children changed in a positive way from hospitalisation

Appendix H

Health Review Ethics Committee Approval

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Health Research Ethics Committee (HREC)
Approval Notice

New Application
18/04/2018
Project ID :1710
HREC Reference #: S17/10/238
Title: The perceived effects of long-term hospitalisation of children with multidrug-resistant tuberculosis in the Western Cape – a qualitative analysis.

Dear Miss Kyla Meyerson,
The **New Application** received on 27/10/2017 11:29 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 18/04/2018 and was approved.
Please note the following information about your approved research protocol:
Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**
Please remember to use your **Project ID [1710]** on any documents or correspondence with the HREC concerning your research protocol.
Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.
After Ethical Review
Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.
The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.
Provincial and City of Cape Town Approval
Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-researchapproval-process.
Research that will be conducted at any tertiary academic institution requires approval from

the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.
We wish you the best as you conduct your research.
For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/1710
If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.
Yours sincerely,
Francis Masiye,
HREC Coordinator,
Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number: REC-130408-012 (HREC1)·REC-230208-010 (HREC2)
Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number: IRB0005240 (HREC1)·IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; *the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition)*; as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.