

The function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time

By

Kirstyn Star Botha

Dissertation in partial fulfilment of the requirements for the degree

MMus (Music Therapy)

Department of Music

Faculty of Humanities

University of Pretoria

Supervisor: Ms. Karyn Stuart

Co-Supervisor: Mrs. Andeline Dos Santos

November 2017

Name of student: Kirstyn Star Botha

Address: 10 Sally Close,
Milkwood Park, 7975

Cell phone number: 0714822053

E-mail address: kirstynstar@hotmail.co.uk

Student Number: 16284578

Supervisors: Ms Karyn Stuart
Mrs Andeline dos Santos

Abstract

This qualitative research study explored the function of music therapy in the transformation of role identities for clients who had been in paediatric palliative care for an extended period of time. This study aimed to explore the value of music therapy in this transformation, as well as within the context of paediatric palliative care in South Africa.

The research took place at a paediatric oncology unit at a local Cape Town Hospital where three participants were selected to receive music therapy sessions over a period of eight weeks. The session notes were analysed and six video excerpts were selected. Through the use of thematic analysis and coding hierarchies four themes (or “role palettes”) emerged from the data: the sick role palette, the mastery role palette, the resilient role palette and the theme of mutuality. It appeared that music therapy could have been a facilitator in the process of a shifting in role palettes.

Key terms: Music Therapy; Paediatric Palliative Care; Terminal Illness; Identity; Adolescents; Song-writing; Role Identities

Table of Contents

Abstract.....	iii
Chapter One: Introduction.....	1
1.1 Background and Context.....	1
1.2 Aims.....	2
1.3 Research Question.....	2
1.4 Overview of dissertation.....	2
1.5 Conclusion.....	3
Chapter Two: Literature Review.....	4
2.1. Introduction.....	4
2.2. Paediatric Oncology.....	4
2.3 Paediatric Palliative Care.....	7
2.4 Paediatric Palliative Care in South Africa.....	9
2.5. Music Therapy in Palliative Care.....	10
2.6. Development of identity.....	12
2.7. Identity and Music Therapy.....	14
2.8. Conclusion.....	16
Chapter Three: Methodology.....	17
3.1. Research Paradigm.....	17
3.2. Qualitative Methodology.....	17
3.3. Research Design.....	17
3.4. Participants.....	18
3.5. Data Collection.....	19
3.5.1. Participant Observation.....	19
3.5.2. Song-Writing.....	20
3.6. Data Preparation.....	20
3.7. Data Analysis.....	21
3.8. Research Quality.....	21
3.9. Ethical Considerations.....	22
3.9.1. Informed assent and consent.....	23
3.9.2. The Dual Relationship: Therapist as Researcher.....	24
3.10 Conclusion.....	24
Chapter Four: Data Analysis.....	26
4.1 Introduction.....	26

4.2	Participants	26
4.3	Data Selection	27
4.3.1	Selecting Video Excerpts	30
4.4	Coding	32
4.5	Developing Categories.....	35
4.6	Themes.....	36
4.6.1	Theme 1: Sick Role Palette	37
4.6.2	Theme 2: Mastery Role Palette	37
4.6.3	Theme 3: Resilient Role Palette	38
4.6.4	Theme 4: Mutuality.....	38
4.7	Conclusion	39
Chapter Five: Discussion		40
5.1	Introduction	40
5.2	The Sick Role Palette	40
5.3	The Mastery Role Palette.....	42
5.4	The Resilient Role and Personal Growth	43
5.5	Shifting between Role Palettes	44
5.6	Mutuality and its potential role in Transformation	46
5.7	The Function of Music Therapy.....	48
5.8	The Value of Music Therapy in Palliative Care.....	50
5.9	Conclusion	52
Chapter Six: Conclusion.....		53
6.1	Introduction	53
6.2	Summary of the Findings	53
6.3	Limitations	53
6.4	Recommendations for future research	54
6.5	Conclusion	54
Chapter Seven: Reference List		56
Chapter Eight: Appendices		64

Chapter One: Introduction

1.1 Background and Context

Growing up as the daughter of a radiotherapy service engineer, and being able to visit oncology units on a regular basis, the field has always been a fascination of mine. During a music therapy internship at a paediatric convalescent hospital in Cape Town, I encountered several children in the palliative care ward who suffered from brain tumours. Through interaction and musical engagement with a particular client, her individuality began to emerge through the music therapy process. The role she played in sessions changed from non-responsive to being commanding in her mannerisms and actions. This ignited an interest for me in the role identities that children who are facing a terminal illness may experience and express.

The concept of role identities is situated within Identity Theory. According to Stryker (2000), the core of an identity is the ability to categorise oneself as the occupant of a role and to incorporate the meanings and expectations associated with that role into the self. This can be achieved through the process of identification. Identification occurs when the self is reflexive in that it can take itself as an object and categorise itself in relation to other social classifications (Stets & Burke, 2000). Marcia (1980) writes that the self-constructed structure of identity is not static, but rather dynamic. It is the dynamic characteristic of identity that is of most value to the current study, as the intervention was designed in order to attempt to facilitate identity transformation.

According to Linebarger, Ajayi and Jones (2014) palliative care and life limiting illnesses evoke challenges for adolescents in the areas of physical development, autonomy, identity, cognition and spirituality. Adolescents face an identity paradox as they try to reconcile their previously known self with their "sick identity". This paradox can be seen when some patients become defined by their illness and their identity shifts to the role of patient rather than the role of a teenager who is suffering from an illness.

Music therapy is worth investigating as an intervention in this regard as it allows for exploration of oneself through freedom of expression (Tervo, 2001). Through this exploration there is a possibility for identity shifting.

Forrest (2001) investigated the need for elderly patients who are facing terminal illnesses to explore and confirm their identity. The elderly patients in Forrest's study were facing death, while reconfirming who they were, their culture and where they fit in society. This research

investigated the role that music therapy could play in this process. The author found that music therapy appeared to assist with the rediscovering of identity in palliative care, but recommended further research.

While the research undertaken by Forrest was conducted with the elderly in palliative care, the current research study investigated the role of music therapy with adolescents in palliative care. Tervo (2001) writes that music therapy can be a powerful tool for accessing the identity of an adolescent, providing them with a safe space to explore who they are and to move forward in their development.

The local paediatric ward where this research study was conducted was based in a large government hospital. The hospital took the initiative to place the paediatric wards of various specialties together in one section of the hospital which was then named the 'Children's Hospital'. The hospital aims to improve diagnosis and care of children and new-born babies. A full range of services are available to the children which are managed by multi-disciplinary teams consisting of specialist paediatricians, paediatric surgeons, general paediatricians, nursing staff, occupational therapists, physicians and dieticians.

1.2 Aims

This study aimed to explore the function of music therapy in the transformation of role identities for adolescent clients who had been in paediatric palliative care for an extended period of time. Due to their illness, patients in palliative care are in a critical stage of their lives and the aim of this study was to examine what value music therapy may have for these patients.

1.3 Research Question

The main research question for this study was:

What is the function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time?

1.4 Overview of dissertation

The second chapter presents a review of the literature concerning paediatric palliative care and the value of music therapy within this setting. Current literature regarding paediatric

palliative care in South Africa is discussed, as well as the gap in literature wherein this study situates itself. Finally, literature regarding identity development and how music therapy can be used in this regard will be reviewed.

The third chapter will discuss the nature of qualitative research and the interpretive paradigm this study is situated within. The selection of participants, method of data collection, data preparation and data analysis will be discussed, concluded by a discussion of research quality and the ethical considerations taken throughout the study.

This will be followed by a chapter discussing the process of data analysis and the findings that emerged. A clear description of the analysis process will be presented followed by a descriptive account of the findings.

The fifth chapter will entail a detailed description of the findings in relation to the aim and research question of the study. The findings will be contextualised in relation to the literature reviewed in chapter two. The final chapter will conclude the study with a brief summary of the findings, as well as limitations to the study and recommendations for further research in this field.

1.5 Conclusion

This chapter discussed the context within which this research study was founded and presented the aim of the study and the research question. The chapter continued by discussing a brief overview of the study and the chapters within.

The following chapter will review the current literature in fields related to this study. This includes paediatric palliative care, music therapy in this setting, the development of identity and the benefits of music therapy in this development.

Chapter Two: Literature Review

2.1. Introduction

This chapter will discuss the literature within the areas of paediatric oncology, paediatric palliative care, palliative care in South Africa, the development of identity, and how music therapy can be a key tool in this regard. The chapter will begin with the area of paediatric oncology as it sets the foundation for the needs associated with adolescents in these unusual circumstances. It will continue with a discussion on paediatric palliative care, this field within a South African context, how music therapy is beneficial in this setting; followed by a detailed discussion on identity and where the research study is locating itself within this vast field. Through the discussion of the aforementioned areas the research study will situate itself within the gaps of the literature.

2.2. Paediatric Oncology

While not all of the participants in the current research study were specifically diagnosed with cancer, this topic of knowledge was integral for the researcher to understand as it assisted in conceptualising the needs of adolescents when faced with these unusual circumstances.

According to Linebarger et al. (2014), children who have been diagnosed with life threatening illnesses are now surviving longer than they were a few decades ago due to the advances of medical treatment. Abad (2003) elaborates further, stating that due to the advance in research and treatment of childhood cancers, many children have prolonged lifespans. Therefore, in addition to adolescents who are diagnosed with cancer, more children with diagnoses of cancer are reaching adolescence (Su-Ming Yeo & Sawyer, 2009).

In order to anticipate certain palliative care issues, it is helpful to maintain an awareness of typical physical and psychosocial development in the adolescent (Freyer, 2011). There are several developmental and psychosocial concerns that are achieved in adolescence, which roughly ranges across a ten-year span. Three sub-stages can be identified. The first is early adolescence (10 – 14 years of age) at which time there is a focus on a shift in attachment from parents to peers. The second, or middle sub-stage (15 – 17 years of age), involves the consolidation of self-image, experimentation, feelings of achievement and power, and advancement in logical thought processes such as abstract thinking. The final sub-stage (extending to 20 years of age) is characterised by an increased sense of comfort with oneself, increased awareness of others and appreciation for meaningful relationships. This perspective

on adolescence was developed within a Western context and therefore is simply one approach to the development of adolescence. Within an African context, interpersonal aspects in relation to social aspects are crucial to informing personal identity, and therefore the development thereof (Adams & van der Vijver, 2017). This will be elaborated on later in the chapter.

According to Kang et al. (2009), adolescents experience a unique type of suffering in terminal cancer care due to the combination of their illness and the difficulties that arise during their developmental stages, such as hormonal changes, identity crises etc. A study in 2012, conducted by Zebrack and Isaacson investigated the psychosocial needs of adolescents with cancer. They found that during the critical development from childhood to adulthood, in combination with a life-threatening illness, adolescents in their study encountered many challenges. In ordinary development they faced the challenges of being comfortable with who they are, identity development, sexual development, navigating conscious awareness of their bodies and the relationships they create. When confronted with cancer, additional challenges arise such as being faced with premature mortality, increased dependence on parents and family, changes in physical appearance, disruptions to social life and potential loss of reproductive capabilities.

Freyer (2011) states that the dying adolescent experiences many barriers to typical physical and psychosocial development. These barriers include disruptions to daily life caused by prolonged hospital stays and outpatient visits; decline in physical strength and abilities; neurocognitive deficits; and even medication regimes that may alter normal routines, school attendance and socialisation, contributing to poor self-image. Other challenges that may be experienced by an adolescent in palliative care could be effects of social rejection and social isolation, a lack of sexual outlets and the forming of normal interpersonal relationships.

The psychosocial needs that adolescents experience when entering palliative care include a grounded support system of family and friends, in-depth communication from doctors and to be involved in the decision-making process regarding their care (Linebarger et al., 2014). A study by Nass et al. (2015) has shown that attending to the needs of adolescents in palliative care improves the quality of life of both patients and their families.

Zebrack and Isaacson (2012) state in their study that adolescents in cancer care are encouraged to remain independent and active, cope with treatment related adverse effects, seek and understand information, manage stress, seek social support, and remain positive. However, this is challenging for an adolescent suffering with cancer and, therefore, psychosocial support is imperative to their quality of life. Throughout the continuum of care for this particular clientele, Zebrack and Isaacson identified five domains of stress and coping,

namely informational, practical, interpersonal, emotional and existential. Zebrack and Isaacson go on to elaborate on each domain as follows.

Informational issues include deciding how much and what information needs to be communicated to the adolescent in terms of their needs and emotional stability. For some patients, information can be distressing, yet for others it can be empowering. Zebrack and Isaacson (2012) then state that the decision is left to the parents, or guardian of the patient regarding what and how much information should be relayed to the patient. However, their study was conducted in America and according to the Health Professional's Council of South Africa (2008), the patient has the right to be involved in the decision-making process on matters affecting their own health.

The second domain identified by Zebrack and Isaacson (2012) is that of practical issues. These relate to how the illness is practically affecting the patient. This may be in relation to the receiving of treatment and diagnostic reports, concerns of future unemployment and socioeconomic issues. A life disrupted by cancer results in a range of concerns for adolescents, which leads to the third domain of emotional issues. Adolescents have the cognitive capacity to understand the severity of their illness and frequently exhibit distress and anxiety relating to the possibility of death, cancer recurrence and late effects. Late effects are conceptualised as the problems that are not evident or identified after treatment, but may develop as a consequential effect of the treatment on organ symptoms or psychological processes such as depression (Stein, Syrjala & Andrykowski, 2008). These include physical changes such as hair and weight loss, catheters, amputations, surgical scars and skin coloration, as well as fear of their body not returning to the way it once was or of being rejected due to their physical appearance (Zebrack & Isaacson, 2012).

Along with concerns of physical change, adolescents express future concerns. These concerns could include access to health and life insurance, jobs and career opportunities as well as hereditary risk of passing cancer on to their own offspring. During adolescence, individuals begin to realise that they are sexual beings and, therefore, there is special consideration related to self-image. These concerns refer to interpersonal issues, the fourth domain. Interpersonal issues suffered by cancer patients may also include heavy reliance on family support; where the patient was once increasing their independence, this illness has caused them to regress. The issue of disclosing a cancer diagnosis to close friends and intimate partners is particularly salient to this clientele, and may be challenging due to the fear of possible rejection and alienation. Such issues may result in the adolescent feeling deprived of companionship and support, leaving them feeling ultimately alone (Zebrack & Isaacson, 2012).

Finally, the last domain of concern is that of existential and spiritual issues. This domain is particularly relevant to the research question and the findings. Improving quality of life in terms of spiritual care within palliative care is a recently recognised dimension (Puchalski et al., 2009). Spirituality is a patient need. It affects health-making decisions as well as health care outcomes such as quality of life.

Kang (2009) elaborates on existential issues by stating that finding meaning and purpose in life is a fundamental human desire and when this may not be achievable, a person can experience existential emptiness. Existential emptiness is a difficult psychological issue for a person as it relates to a lack of meaning in life (Frankl, in Kang, 2009). This status of existential emptiness is one in which a person has lost meaning in life, in combination with despair and helplessness. Therefore, this area may be one of importance when assisting adolescents with terminal cancer. Due to the life-threatening nature of their illness it may be of importance to encourage them in the continuation of their search for the meaning of life.

In the face of this life-or-death situation, which is uncommon for adolescents, they are faced with a disruption to their perceived normal order of life and the way that they assumed the world to work. This causes their faith in the predictability and continuity of life to be threatened. Although this uncertainty may be a cause of distress, it may also be a catalyst for personal growth, greater awareness of life's purpose, increased and deepened appreciation for life, as well as the development of confidence, resilience and optimism (Zebrack & Isaacson, 2012).

The area of paediatric oncology is a well-researched field, providing understanding into the needs of adolescents, their development and how a life-threatening illness could have an effect on this. The chapter will continue by discussing the unique needs of children in palliative care, where music therapy can be of assistance and where there is a lack of research, particularly in regard to South Africa.

2.3 Paediatric Palliative Care

Palliative medicine was originally defined as being necessary when curative approaches were no longer viable. However, there has recently been a shift in this frame of thinking and palliative medicine is encouraged to be integrated into the continuum of care for all patients (Luck, 2014). As the WHO definition of palliative care entails an active role of care in the holistic treatment of a patient, this is beneficial to the patient regardless (WHO, 2011).

Foster, Lafond, Reggio and Hinds (2010) states that the aim of paediatric palliative care is to enhance life, decrease suffering and aid in personal and spiritual growth. Paediatric palliative

care is the active total care of the child's body, mind and spirit, as well as providing support to the family. This is achieved through treatment of pain and other problem areas, whether these be physical, spiritual or psychosocial (Liben, Papadatou & Wolfe, 2007).

In the International Children's Palliative Care Network paper entitled *Children's Palliative Care in South Africa – The Facts* Amdey (2010) states:

Children's palliative care cannot claim to protect the quantity of a child's life. But children's palliative care can claim to protect the *quality* of a child's life, and of course to relieve suffering. There can be few things more important or more valuable in life than to relieve the suffering of a child and to help the child live the life they have as fully as possible (p. 2).

The concept of suffering can be defined as an experience that results from a threat to an individual's personhood. Personhood may refer to personality traits, character, cultural background, life experiences and the individual's inner life, such as their dreams and aspirations (Liben et al., 2007). One's personhood may suffer loss as roles change or decline, and as one is unable to fulfil the expectations associated with the role one embodied prior to diagnosis. Suffering can occur as relationships become challenged and one is unable to fully express one's emotions (Cadrin, 2006). Suffering may be explored through therapeutic work using non-verbal means of expression, such as drawing and music. According to Liben et al. this way of working can facilitate an individual's expression of the depth and complexity of cognition and emotion while placed in palliative care. Anticipatory grief and suffering can be expressed in this non-verbal medium, but may also be expressed through verbal means in the context of a client-therapist relationship.

Liben et al. (2007) state that emphasis in research regarding suffering in palliative care is placed largely on that caused by the loss of life as yet un-lived. Anticipatory grief may lead to feelings of being in a liminal space which, according to Carter (2017), is a possibility for infants, children and adolescents in paediatric palliative care, as well as their families. Paediatric palliative care involves numerous transitions and thresholds of uncertainty for patients in palliative care and their families.

Carter (2017) elaborates by stating that the paediatric palliative care patient could feel "stuck in places betwixt and between" (p.297) a past life that may have been rich with purpose and relationship, and a chronic, or critical, illness; between past bounds of illness and an uncertain path ahead, which may be towards death. Ruud (1998) describes liminal states as characterised by ambiguity, confusion, and dissolution of conventional meaning and fixed points in life. This concept of liminality gives validation to the unusual circumstance of the child

patient and her or his parents, as well as to the ambiguity the patient may be grappling with, having been diagnosed with a life-threatening illness.

The task of the palliative care clinician is to utilise their understanding of this stage of treatment to offer support to the patient and family. They may assist with meaningful reflection, matters of psychosocial and spiritual identity, as well as aiding the families in exploring any sense of meaning and boundedness. Through this support, the patient and their family may gain enhanced autonomy, advocacy, empowerment or simply acceptance of a changed life with chronic illness or the end of life (Carter, 2017).

Quality of life can be seen on a spectrum from suffering on one end to feeling whole on the other end (Liben et al., 2007). The task of the palliative care clinician is to assist the child, and their family, to find their way along the continuum as far as possible from suffering to wholeness. As in the context of this study, the music therapist forms part of the palliative care team, taking on responsibilities and tasks to support the enhancing of quality of life.

2.4 Paediatric Palliative Care in South Africa

While the area of palliative care is a well-researched topic internationally, there is a lack of research concerning paediatric palliative care in South Africa. This may be due to the general lack of paediatric palliative care in general (Connor et al., 2014), as it is still in its infancy. Luck (2014) explains that in South Africa there is an underestimate of 800,000 children in need of generalised palliative care, and a further 300,000 in need of specialised palliative care treatment. The need for this type of care in South Africa arose with the growing HIV/AIDS epidemic and the increasing number of children born infected with the virus (Marston et al., 2012).

Connor et al. (2014) state that the capacity for South Africa to deliver paediatric palliative care is limited, with less than 5% of the children who are in need of care physically receiving it. This is due to lack of education of paediatric palliative care practitioners, lack of integration of paediatric palliative care into the primary care setting, fear of opioid use and lack of awareness of the needs and services provided by paediatric palliative care.

However, Marston, Nkosi and Bothma (2012) state that South Africa is the pioneer in paediatric palliative care in Africa. The first palliative care program began in 1992 in Bloemfontein and since then a total of 60 programs have been initiated and this continues to expand. The majority of these programmes are situated in the Free State due to the St

Nicholas Bana Pele Network project and are, therefore, not distributed evenly across South Africa.

Aside from a handful of studies and surveys there is a general lack of research in the field of paediatric palliative care in South Africa. While the research regarding music therapy in paediatric palliative care is a well-established field, the research concerning music therapy in paediatric palliative care within a South African context is limited. Therefore, this demonstrates the need of this current research study and the gap within which it can be situated.

2.5. Music Therapy in Palliative Care

Sheridan and McFerran (2004) explain that paediatric palliative care is unique, compared to adult palliative care as it may support children for many years throughout all the stages of their illness. In some cases, this may be from birth to death. O'Callaghan and Barry (2010) state that music therapy in palliative care can be described as the professionally informed and creative use of music within a therapeutic relationship with people identified as needing biopsychosocial or spiritual help, increased quality of life, or who desire to further self-awareness. Music therapy may be useful in addressing physical, psychological and social needs, as well as enhancing the quality of life for paediatric patients (Reid, 2016).

In palliative care, music therapists use methods such as improvisation, song writing, singing and instrument playing, lyric analysis, guided imagery and music, and music therapy relaxation techniques to assist in treating the many needs of patients. The needs addressed by music therapists include social, emotional, cognitive, physical and spiritual (Hilliard, 2005). Aldridge (1995) states that when progress of a disease increases personal isolation due to the deteriorating health of a patient, then the music-therapeutic relationship is important for maintaining interpersonal contact within a non-judgmental space that is free for expression.

Reid (2016) states that music therapy can be used when patients are placed in isolation rooms during their treatment. Here, children may experience physical separation, decreased social interaction, reduced stimulation and physical activities. Emotionally, loneliness, depression, anger, confusion, rejection and lowered self-esteem are often experienced.

In a study conducted by Reid (2016), music therapy is shown to offer children in this setting the opportunity for interpersonal interaction, increased control, shared musical experiences, self-expression and the development of adaptive coping skills. Environmental stressors such as anxiety, withdrawal and loss of control can also be addressed.

According to Abad (2003), music therapy interventions have been used with adolescents in palliative care to assist in coping with pain, anxiety, isolation, increased dependency, loss of control and stimulus deprivation. However, they have not been used, specifically, to support adolescents in the 're-discovery' of their identity. It would seem that no further studies have been conducted in the area of identity 're-discovery' since Abad made this statement, demonstrating the importance of the current study.

Music can enhance areas of an adolescent's health, including identity formation, competence, resilience and connectedness when in palliative care. Moments of fun, laughter and play enabled by music therapy can be invaluable for families when a child is in palliative care. Creative experiences in the hospital environment are important as they promote healthy aspects of the patient. The music therapist can flexibly and sensitively offer adolescents and children, the opportunity to keep living while in palliative care (Reid, 2016).

O'Callaghan (2012) showed that song-writing is a powerful technique to use in palliative care. It facilitates expression of suppressed feelings, instils feelings of contribution to the world, provides the client pleasure and contributes to self-efficacy, all while assisting the client in expressing messages of importance to family and friends (O'Callaghan, in Clements-Cortes, 2016).

Clements-Cortes (2016) writes extensively on the use of song-writing. She elaborates on the many benefits of song-writing that include: offering the patients opportunities to express creatively through both the words and music; it may be less threatening than other forms of creative writing; provides varied opportunities to promote physical and social well-being; verbally and musically validates emotional expression; and may offer opportunities for deeper emotional sharing and therapeutic response. The song melodies may inadvertently offer comfort and creating new lyrics for well-known music may encourage expression of thoughts and feelings. When writing songs one may feel pride about both the lyrics and musical accompaniment (Clements-Cortes, 2016).

Clements-Cortes (2016) explains that, in more recent research, song-writing has continued to be a helpful technique for clients in palliative care as it assists them in the expression of feelings and enables discussion with family and friends, providing the framework to discuss their feelings and fears. Along with song-writing, the use of clinical improvisation has proved beneficial for patients in palliative care. The benefits include release and resolution of difficult and painful emotions; helping the client to build a deep and therapeutic relationship with the therapist, which assists the client in feeling understood; assisting the client to access unconscious feelings and issues and to process them, which may include anger, existential

loneliness, fear, jealousy and anxiety; as well as increasing comfort and decreasing anxiety (Clements-Cortes, 2016).

According to Clements-Cortes (2016) four models of music therapy are largely used within palliative care. Within these models receptive, re-creative, creative and combined techniques are used. Song-writing and improvisation are used within the model of creative music therapy, although they are also used in other models. The combined technique involves, for example, the creation of a musical life review in which the client is provided the opportunity to review significant and unique aspects of their lives, celebrate their accomplishments, process any regrets they may have, and raise self-esteem.

Cadrin (2006) explores the use of legacy work in palliative care. She states that legacy work is the process in which one creatively expresses and documents one's life. This may be beneficial in palliative care as it assists patients in communicating and clarifying their beliefs, values, experiences, life stories and life's meaning for those they leave behind. Music therapy can offer a unique opportunity in the creation of musical life reviews and legacies, due to the very nature of music. Music may enable insight. A diagnosis of a terminal illness may itself also provoke insight. One may find the desire to reflect on one's accomplishments, seek understanding and make amends for past events that have not been reconciled.

Music can play a psychological function in adolescents in terms of four areas: interpersonal relationships, identity, agency and emotional field (Laiho, 2004). The current research study draws on the definition of agency provided by Laiho, referring to personal control and competency, a recognition or understanding that one can be the cause of events, feelings of mastery, self-determination, resisting authority and achievement motives.

These four areas refer to different aspects of psychological goals or functions that are central to the development of adolescence, can be supported by musical activity, and contribute to the development of agency, interpersonal relationship, emotional insight and identity.

2.6. Development of identity

Adolescence is defined as the period of life generally between the ages of 11 and 19 years, beginning with the appearance of secondary sex characteristics and ending with the cessation of somatic growth. This period is not only characterised by physical development, but the development of self-esteem, independence, awareness, identity and social skills (Freyer, 2011). Knowing who one is and having a clear sense of identity is a crucial aspect in healthy psychosocial development (Jacobs & Collair, 2017).

Identity development continues throughout the lifespan, according to Erikson's (1994) theory of identity. However, it is most impressionable in the early stages and continues to be so in adolescence (Marks et al., 2002). Marcia (1980) built on Erikson's theory and explained that adolescence is a transition period. This is particularly so regarding the shift from one's psychosocial concerns based on other's expectations to a focus on one's own unique organisations of beliefs, history, shortcomings, skills and goals.

Western researchers such as Marcia and Erikson focus largely on the individual and ego identity, in keeping with Western emphasis on the individual. However, as stated by Phinney (2000), identity development involves the formation of both personal and group identity. Group identity is of particular importance amongst members of minority groups within a multicultural society, such as Africa and South Africa. In non-Western, collectivist cultures, the emphasis is placed largely on one's relationship to the group (Phinney, 2000).

As mentioned, identity development neither begins nor ends with adolescence. However, what is important about adolescence is that this is a time where physical development, cognitive skills and social expectations coincide (Marcia, 1980). This enables adolescents to sort through and synthesise their childhood identifications in order to construct viable pathways towards adulthood.

Marcia (1980) is a highly influential Western writer in the field of identity in adolescence and his research was drawn upon for this study as it is still a primary resource in this field. This can be seen in the work of Kroger (2010) and Finkelstein (2005) who base their research upon Marcia's theory. Marcia proposes that identity is a "self-structure: an internal self-constructed dynamic organisation of drives, abilities, beliefs and individual history" (p.159).

Marcia (1980) elaborates that this structure is not static, but rather dynamic. It is the dynamic characteristic of identity that is of most value to the current study, as the goal of the music therapy process was to facilitate identity transformation. Marcia states that, as elements, such as awareness of one's strengths and weaknesses and reliance on external sources to evaluate oneself are constantly being added and discarded, the entire gestalt may shift. One conceptualisation of how such a transformation could occur rests on an understanding of role identities. This notion is situated within Identity Theory.

Identity Theory is a microsociological theory that aims to explain an individual's role-related behaviour (Hogg et al., 1995). In Identity Theory the core of an identity is viewed as the ability to categorise oneself as the occupant of a role and to incorporate the meanings and expectations associated with that role into the self. This can be achieved through the process of identification that occurs when the self is reflexive. The self is reflexive when it can identify

itself as an object and categorise itself in relation to other social classifications (Stets & Burke, 2000).

A person does not encompass one role alone, but instead shifts and changes these roles according to their social circumstance (Stryker & Burke, 2010). A person may be seen as living their life in a small and specialised network of social relationships, doing so through roles that endorse their participation in these networks. Identity Theory adopts the principle of persons having as many selves as the groups within which they interact. Within this theory, social roles are expectations attached to positions occupied in networks of relationship and, therefore, identities are internalised role expectations. The theory states that role choices are a function of salient identities and that identities within the self are organised in a hierarchy. This reflects the importance of the hierarchy as an organisational principle in society (Stryker & Burke, 2010).

Identity salience is the probability that an identity will be provoked across a variety of circumstances and situations (Stryker & Burke, 2010). This is further emphasised by Stets and Burke (2000) who state that identities can be activated through the concept of salience: depending on the situation the person finds themselves, a particular role will be activated dependent on the situation.

Role identity theorists focus on the individual meanings and expectations that are tied to a particular role and the behaviours a person enacts in that role while interacting with others. This focus includes the negotiation of meanings for identities and situations, and how they fit together to provide a situated context for interaction. By taking on a role identity a person identifies with the expectations and meanings of that role in relation to other roles in a group, and then acts accordingly to best represent that role identity and preserve its meanings and expectations. These meanings and expectations differ across persons in the set of roles activated by the situation (Stets & Burke, 2000).

2.7. Identity and Music Therapy

According to Ruud (1997), music is ever present in our daily lives, therefore it frames and anchors many of the situations that are used as material in the process of identity formation. Identity is a process, constructed as we make a model of who we want to be in the world and where we want to belong.

Furthermore, Ruud (1997) states that music may serve as the raw material in the building processes of life orientations and values. It may be seen as a way of anchoring important

relationships to others, framing our situated-ness in a particular time and space, and positioning ourselves within culture and ethnicity. Music provides transcendental experiences that may strengthen the formation of identity in the sense that we may experience purpose, meaning and significance in our lives.

Daykin et al. (2007) conducted a study on the accounts of young adults and adults with cancer participating in music therapy as part of a programme in supportive cancer care. The importance of identity and the role of creativity in the process of individuation were key themes that emerged from this study. The benefits of how music therapy can be used as a medium to express this identity emerged from the findings of this study. The music therapy sessions enabled expression and elaboration of material that was articulated within a nonverbal context.

This was beneficial in the restoration of identity, empowerment, relief of suffering and helping to find meaning in challenging situations. Music making in a therapeutic setting represents a potential space where creativity can be explored. After illness, there is a strong need to claim and reinstate creative identity that can be provided through the potential space offered by music therapy (Daykin et al., 2007).

Music therapy provides an opportunity for intimacy within a creative relationship. This relationship is equal and non-judgemental. Within this relationship the patient is encouraged to creatively explore identity in light of illness (Aldridge, 1995).

Amir (2012) argues that music can play a vital role in formulating, developing and expressing individual identities. This is possible as it involves many aspects of daily life, provides a means to share emotions, meanings and intentions, as well as eliciting deep and profound emotions within us. It is in this way that music can play an integral role in formulating and expressing individual identity.

This was taken further by O'Callaghan and Barry (2010) with specific relation to children in palliative care. They state that music therapy can be utilised as a safe haven for internalising a healthy self-image alongside patient identity. Music can be used as a transitional space that holds and nurtures while supporting the exploration of new realities. A child's perception of themselves can shift due to their 'non-illness' identity being acknowledged.

Forrest (2001) conducted a study in which she examined the underlying mechanisms used in the construction of identity and group identity of elderly patients in palliative care. She explored the evolution of identity as well as the use of music as a means to construct and express identity. Finally, through the use of a case study, the role of music therapy was explored in addressing issues of ethnicity and identity. Forrest found that music therapy allowed clients to

explore their present situations in relation to their memories, experiences and important life events. She found that music therapy facilitated exploration of issues regarding ethnicity and identity in relation to the client's immigrant status.

Music can be used to discover identity on three inter-related levels, according to Forrest (2001). The first of these is a social level where music can be used to explore culture, social boundaries and social contexts. Secondly, music can be used as a tool to develop personal identity; the music allows a safe space to test boundaries, hierarchies and further develop identities. The third level is where music may define identity historically by reminding the participant of events passed. While Forrest's (2001) study dealt with the elderly exploring their identity and ethnicity, the current study was looking at similar challenges with regard to adolescent clients exploring role identities.

2.8. Conclusion

Music therapy in paediatric palliative care is a well-established field of study (Aldridge, 1995; Amir, 2012; Clements-Cortes, 2016; Forrest, 2001; McFerran & Sheridan, 2004; O'Callaghan & Barry, 2010) and so is the field of the use of music therapy in identity development (Daykin et al., 2007; Kang, 2009). Although a few studies mentioned identity within a palliative care setting (Forrest, 2001) the majority of the research focused on the benefits of music therapy for paediatric patients with regard to pain, anxiety and suffering; very few studies focused on the experienced identity of the patient.

The study has been situated within Identity Theory and the exploration of role identities which has been researched extensively (Marcia, 1980; Stets & Burke, 2000; Stryker & Burke, 2010). Through exploring the relevant areas of available research, it has been noted that there is a lack of literature in the field of paediatric palliative care within a South African context. Two gaps in the research in particular serve as areas where the current study can contribute: the use of music therapy in identity work, and how this can take place within paediatric palliative care in a South African context.

The following chapter will discuss the nature of qualitative research and the interpretivist paradigm in which this study is situated. The sample selection, method of data collection, data preparation and data analysis will be discussed, concluded by a discussion of research quality and the ethical considerations taken throughout the study.

Chapter Three: Methodology

3.1. Research Paradigm

This research study is situated in the interpretive paradigm. According to Terre Blanche et al. (2006) interpretivism aims to understand the way that people make meaning using empathetic understanding. It holds the epistemological position that prioritises people's subjective understandings and interpretations of their own actions and social phenomena. An interpretivist approach gathers people's interpretations and understandings and the social researcher then interprets this through theories and concepts belonging to their discipline (Matthews & Ross, 2010).

The epistemology is subjective as interpretive research calls for the researcher to be empathetic and maintain a subjective relationship with participants. The ontology of an interpretive paradigm is relativistic in that it assumes that our individual reality is built inter-subjectively through meanings and understandings (Terre Blanche et al., 2006).

3.2. Qualitative Methodology

The ontology of an internal reality of subjective experience combined with an empathetic epistemology leads the research to a qualitative methodology. Qualitative research has an emergent design in which the methodology evolves and allows the process to determine the direction of the investigation (Ansdell & Pavlicevic, 2001). This type of research is flexible so as to allow the phenomenon under investigation to reveal itself. The nonlinear quality of qualitative research is of high value in that it does not follow a strict procedural sequence, but responds to the research process in a holistic and intuitive way (Bruscia, 1995).

3.3. Research Design

The research design for this qualitative study was a case study design. A case study involves the intensive, in-depth and focused exploration of an individual or group (Stake, 2005). The common identifiable features of case study research include an idiographic perspective, attention to contextual data, triangulation, a temporal element and a concern with theory (Willig, 2008)

Stake (2005) states that there are three types of case study designs: intrinsic, instrumental and multiple. Drawing from these classifications, the current study used an instrumental case study design, which is the study of a case that focuses on providing insight into a particular issue. An instrumental case study is employed to provide insight and facilitate the understanding of the issue under investigation. The current research studied particular cases so as to explore the concept of identity in depth and the transformation of role identities within these particular cases.

Each client was meant to receive a total of eight individual music therapy sessions that were to be video recorded. However, due to the nature of this research study only one participant received the full eight sessions. The remaining two 'participants' passed away during the process and, therefore, these two received three music therapy sessions in total. The sessions took place in the paediatric oncology ward of a Cape Town Hospital. Music therapy sessions typically begin with an opening song (greeting song), numerous interventions and end with a closing song (goodbye song). The specific music therapy interventions these sessions entailed included music improvisation and song writing. I exercised flexibility and caution regarding the capacity of the client to participate in therapy on any given day and worked very sensitively in this regard. The work was clinically supervised and I received research supervision during this period.

3.4. Participants

The participants for this study were selected using convenience and purposive sampling. Convenience sampling is a nonprobability sampling technique where individuals are selected because of their convenient accessibility and proximity to the researcher. Convenience sampling is useful when there are limited time and resources available to the researcher (Matthew & Ross, 2010). Due to the nature of the current research study and the limited number of paediatric patients in palliative care, the participants were selected according to convenience sampling.

Purposive sampling is also a non-probability sampling technique in which the sample of selected case studies is chosen in order to best enable the researcher to explore the research question in depth. It includes participants who have key experience with the issue under investigation (Endacott & Botti, 2005).

Within purposive sampling there are numerous approaches to selecting participants. The current study used a homogenous sample. A homogenous sample includes cases that belong

to the same group or have similar characteristics. This is valuable as it enables an in-depth investigation of a particular social phenomenon (Matthews & Ross, 2010), in this case adolescents in palliative care.

The sample size was small, consisting of three participants. According to Matthew and Ross (2010) three participants is a sufficient number for qualitative research. It is not uncommon to have a small sample size in qualitative research due to the in-depth nature of the study. The participants were between the ages of 12 and 17 years old, and had been in palliative care for a time period of longer than a month. There was no language or diagnosis preference and the participants were selected on a 'first come first serve' basis determined in the order in which the consent forms were received.

In the Western Cape there are three languages that are most prevalent: English, Afrikaans and isiXhosa. The researcher is fluent in Afrikaans and English. If a participant's mother tongue was isiXhosa and they did not understand English or Afrikaans then a translator would have been brought in for the sessions, however, this was not necessary.

The participants and their families were approached personally in an informal meeting at the hospital where they were receiving treatment. In the meeting, the research and therapy process were explained to the potential participant and their parent/guardian. There was no pressure placed on any participant or their parent/guardian, to participate in the current study. All participation was voluntary. Information forms for the participants and their parents were available in a language they could understand (see Appendix B and C). Informed assent was requested and received from participants and informed consent was received from their parents/guardians. This was discussed further in the section on ethical considerations.

3.5. Data Collection

Data for this study was gathered in two ways, firstly through participant observation (that took place through video recording and reflective session notes) and, secondly, through the analysis of songs written during the music therapy sessions.

3.5.1. Participant Observation

According to Matthews and Ross (2010) observation is the collection of data through the human senses. It is the act of watching social phenomena in the real world and recording events as they happen. The researcher was observing participants throughout the process of

music therapy and exploring with them how they felt the process may have been contributing towards their sense of identity.

Participant observation is the type of observation that was used in this research study and the observation was carried out overtly; it was explained to the participants at the beginning of the research period that each session was video recorded (Matthews & Ross, 2010). However, permission to be video recorded was first obtained from the participants before the research process began. Video recording of every session as well as reflective session notes were the main forms of data collection. Video recording offers a unique advantage to the participant observer as it provides access to all verbal and nonverbal behaviours, as well as cues that the participant observer may have missed during a session (Bottorff, 1994).

3.5.2. Song-Writing

A second method of data collection was through the gathering of songs composed at the beginning of the research period and at the end. A song-writing process was engaged in in relation to role identity themes in the first few sessions and then a song writing process in the remaining few sessions of the research period. These songs were compared to investigate how the participants made sense of their identity and whether they feel there has been a change in their identity from the beginning of the music therapy sessions to the end.

3.6. Data Preparation

Before data analysis could take place, the data collected needed to be organised into a form that was easily accessible. Throughout the music therapy process detailed session notes were kept in order to capture the full range of emotions expressed by the participants. In the session notes ideas and characteristics related to roles were highlighted. Expression of these roles were then selected in the video excerpts. Excerpts were selected, in collaboration with my supervisors, from the video recordings, that are particularly meaningful in relation to the research questions and rich, thick descriptions (Swanson & Holten, 2005) were written. Exactly how the video excerpts were systematically selected will be discussed further in the data analysis chapter. The songs written were transcribed verbatim by the researcher.

3.7. Data Analysis

The data were analysed using the thematic analysis of Braun and Clarke (2006), in conjunction with the comparative analysis of Gibbs (2007). The integration of comparative analysis was important for the current study as the researcher was coding the songs written early and later in the therapy process so as to draw comparisons.

Thematic analysis is described by Braun and Clarke (2006) as a method for examining, identifying and reporting on patterns and themes within data. Braun and Clarke describe two approaches to thematic analysis: inductive and theoretical. This study made use of an inductive approach as it identified themes that were strongly linked to the data. This form of analysis is data driven and involves a process of coding data without trying to fit it into a pre-existing coding frame.

This study followed the six phases of thematic analysis as set out by Braun and Clarke (2006). These phases include familiarising oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Writing is an integral part of the qualitative research process, unlike quantitative research where writing up takes place at the end. The style of writing needs to be consistent from the beginning of the research process through to the end.

An integral form of data analysis in the current study was the comparative analysis of songs written at the beginning of the research process and ones written at the end. According to Gibbs (2007) there are three components to comparative analysis: coding hierarchy, comparisons and models. A coding hierarchy is a method of grouping codes and organising them into branches in a hierarchy system, in this case from top down. The coding hierarchy organises the data in an ordered format (as the analysis process may generate large numbers of codes), can constitute a form of analysis in itself, prevents duplication of codes and provides clear analysis. The coding hierarchy is the starting point and, from there, comparisons can be made using a table, which is important in the current study as it will provide a format for the researcher to draw comparisons.

3.8. Research Quality

This study was conducted with rigour, transparency and reflexivity so as to provide the best quality research possible. Rigour refers to the thoroughness of a study from the appropriateness of the sample to the completeness of the analysis (Smith, 2005). Rigour is the strict and consequent thoroughness in applying a particular method or analysis. When

rigour is used in combination with creativity this provides for a good qualitative study. It is not limited to finding and confirming what was expected, but rather produces new insights and ways of understanding the people being studied (Flick, 2007).

This study was conducted with transparency so as to be as self-evident as possible. A study is transparent when the way the study was conducted and how the researcher arrived at their findings and conclusions is explained clearly and thoroughly. The research was presented in such a way that allows the reader to understand how decisions were made, how the researcher worked with the cases and how analysis was completed. Through the transparent presentation of the research the reader is provided the opportunity to develop an understanding of how the process developed and, in turn, decide whether they would have arrived at the same conclusions (Flick, 2007).

Reflexivity is important in maintaining research quality as the researcher is involved on an interactional and interpersonal level with the study and the participants. Reflexivity is defined as a process in which the researcher engages in explicit self-aware meta-analysis (Finlay, 2002). Pillow (2003) suggests four reflexive strategies: reflexivity as recognition of self, reflexivity as truth, reflexivity as transcendence and reflexivity as recognition of other. These four strategies can be used independently of one another or together and provide the researcher with a guide for reflexivity.

Throughout this study I, the researcher, maintained constant self-awareness regarding how my views, who I am as a person, how I experience the world, what I know and how I know it could be influencing the observations I was making. Through this self-awareness reflexivity was practiced in the research process. Another example of how reflexivity was carried out through this research process was the focus on the development of reciprocity with the participants – hearing, listening and developing equal relationship - doing research “with” the participants as opposed to “on” them (Pillow, 2003).

3.9. Ethical Considerations

The essential purpose of research ethics is to protect the welfare of research participants. Wassenaar (2006) states that there are four widely accepted philosophical principles that guide ethical research: autonomy, non-maleficence, beneficence and justice. All participants provided voluntary informed assent and had the right to autonomy. Their parents/guardians had the right to informed consent, and the right to decline. The participants' identity remained confidential and their dignity was respected. Non-maleficence means that the researcher

ensured that no harm befell research participants as a direct or indirect consequence of the research. The third principle is beneficence. This obliges the researcher to maximise the benefits that the research can afford the research participants. Finally, justice requires that the researcher treats the research participants with fairness and equity during all the stages of research.

All information obtained during the research process was treated with great care and confidentiality. Data was stored at the University of Pretoria for 15 years. If any other researchers wish to use this data, they must obtain consent from participants and their parents/guardians. Should anyone have chosen to withdraw during the process, all data regarding him/her would have been destroyed, however, this was not the case.

Verbal consent was obtained from the Head of paediatric oncology at the hospital for my research to be carried out, and video recorded. Having acquired conditional ethics approval from the University of Pretoria's Health Science Faculty, ethics approval was then obtained from a Western Cape University, in this case the University of Stellenbosch, which resulted in the Cape Town Hospital formally accepting the proposal.

Emotional distress had the possibility of occurring during this process. In the field of music therapy, one is trained to contain and support emotional distress should this occur. There was no pressure to participate in this study and the aim of the sessions was to provide a supportive space for the participants. However, had emotional distress occurred the researcher would have provided additional sessions so as to process this distress.

3.9.1. Informed assent and consent

The participants, their parents or guardians and the institution received participant information forms that provided details of the research study and what is expected of the participants (see Appendices A, B and C). The participants were made aware that confidentiality was ensured, that all information collected during the process was for academic purposes only, and pseudonyms were used so as to further conceal their identity. Participants' right to privacy and confidentiality was honoured at all times. Participants were made aware that they had the right to withdraw from the study at any time (Ansdell & Pavlicevic, 2001).

After receiving information letters, consent was obtained through three avenues. The institution provided consent allowing the therapist to conduct her research and allowing access to participants (see Appendix D). Assent was obtained from the participants (see Appendix C) while consent was obtained from their parents or guardians (see Appendix B). All participant

information forms, consent forms and assent forms were provided in English, Afrikaans and isiXhosa.

3.9.2. The Dual Relationship: Therapist as Researcher

As the researcher, I took on the dual role of both therapist and researcher. As both researcher and therapist I had to take full responsibility for the clinical relationship with clients as well as the quality, accuracy and trustworthiness of the research material. I am aware that while this dual relationship affords the research process it can also be complicated (Ansdell & Pavlicevic, 2001).

It may be complicated in that each role can create different priorities at different times which may interfere with the other. While my focus as researcher was on collecting data, the main focus was that of therapist and maintaining emphasis on the client's well-being.

The presence of dual relationships is not uncommon in qualitative research. It is a beneficial practice as it enhances the research by adding valuable qualities of intuition and insight as well as the immediate examination of one's work (Aigen, 2008). The researcher collected data during the sessions as opposed to an interview at the end of the therapy process. This was done to ensure that the raw emotions, expressions and experiences of the participants were fully captured in the moment, and that these were as natural as possible.

3.10 Conclusion

This chapter discussed the research paradigm within which this research study is situated. This was followed by discussing the ontology, epistemology and methodological framework utilised to conduct of this study. The chapter continued by discussing the selection process of participants, data collection through observation and song-writing, data preparation and analysis.

Finally, the chapter ended with a discussion on how research quality and ethical considerations were to be maintained throughout the research process. This research study was conducted in an ethical manner and the researcher maintained research quality through rigour, transparency and reflexivity.

The following chapter will explain the process of data analysis in detail and present the research findings. This will include a detailed description of the participants, the process of

data selection, preparation, coding and category formation. Finally, the themes derived from the data analysis process will be presented.

Chapter Four: Data Analysis

4.1 Introduction

This chapter will discuss the process of data analysis and present the findings. The thick descriptions of selected excerpts were analysed using thematic analysis (as developed by Braun and Clarke (2006)) while the codes were also sorted into a coding hierarchy (as proposed by Gibbs (2007)). The phases included analysing the session notes to select appropriate sections; transcribing the selected video excerpts; generating initial codes; sorting the codes into a coding hierarchy; categorising the codes in relation to the research question; and finally drawing themes from these categories.

4.2 Participants

Pseudonyms will be used to protect confidentiality. After discussing this with the participants all decided that they would like to be referred to by their initial. By involving the participants in this process, it afforded them an additional sense of ownership and agency in the research process.

All the participants were receiving palliative treatment at the paediatric oncology unit. Three participants, R, T and F, were chosen according to convenience sampling.

R is a 14-year-old boy who had been diagnosed with Haemophilia, Attention Deficit Hyper Disorder (ADHD) and Hyperparathyroidism (HPT). He had been at the unit for a month. R received the full eight-week process of music therapy sessions. R was engaged and involved throughout the music therapy process, although the quality of this engagement shifted and changed throughout, as will be discussed later. He enjoyed the safe space, a space free from judgement in which he could feel fully supported, and be able to express himself creatively, particularly through writing songs.

T was a 12-year-old boy who had been diagnosed with Leukaemia. T had recently been readmitted to the unit due to his rapid health decline. T had been in palliative care for a period of a few months. He was a frail, petite boy who demonstrated excitement and enjoyment when offered the opportunity of creating music in music therapy. T received one music therapy session in which he showed agency in his musical participation. Subsequent to this session T passed away.

F was a 17-year-old boy who had been diagnosed with Fanconi anaemia, a rare form of anaemia in which there is a decreased production of all types of blood cells. F had been in palliative care for a number of years. F was very ill and unwell for the majority of my visits to the hospital. F received two music therapy sessions during the eight-week music therapy process. His form of participation in these two sessions changed due to a decrease in his health. In the first session F was actively involved in music-making for roughly ten minutes, but then withdrew as he experienced pain exacerbated by overexertion. In the second session F participated through passive engagement, receiving receptive music therapy, due to his weakened state and inability to move. Sadly, F passed away at the end of the process.

4.3 Data Selection

Data were collected through participant observation as well as the collection of written songs. Participants were made aware of the video-recording of all sessions for this purpose. Session notes were written after each session throughout the research process. These sessions notes captured immediate observations, participant behaviour and emotional expression, significant moments in the music therapy process, as well as the thoughts and feelings of the therapist (full session notes can be seen in Appendix E).

These session notes were then read in order to inform the selection of appropriate video excerpts. Sections of the session notes were highlighted when characteristics associated with a particular provisional role emerged (the final identification and description of roles was determined only through the full data analysis process). Two examples are included in Table 1. The first shows an example from a session with T and the second from a session with R. Text coloured green indicates characteristics associated with the provisional role of mastery. Text coloured purple indicates characteristics associated with deeper emotional insight, reciprocity and the therapeutic alliance. Text coloured yellow indicates characteristics associated with being guarded and defensive and text coloured blue indicates the need for structure. The full list of provisional roles with their corresponding colours will be presented momentarily (in Table 2).

I offered the choice to T to draw and he said yes. However, as I was prepping this he began to play guitar again, I sang as I got the supplies ready. I took the opportunity, as this felt spontaneous and true to him, whereas drawing felt less natural and more forced, to move back to the instruments and play with him.

T began strumming a more controlled pattern and singing a song he knew. I played the djembe with him and he stopped playing and tried to teach me the words. There was something in the way he stopped to teach me the words that was special and profound.

While the time actor may be due to R's ADHD it could also be attributed to the relationship felt in this improvisation and as a defence to stop, therefore withdrawing from the connection. There were moments in the improvisation where the music was harmonic but then other moments where it was atonal and chaotic.

R experimented with different sounds on the keyboard, looking for a new sound for our new song. This song had to have the chorus of a Chris Brown song and then we wrote the lyrics for the verses. Once again linking to R's need for the structure, or to do things according to a certain mandate. However, now he is allowing himself to experiment within this structure by adding in his own words for the verses. R chose the theme for the song as Love. Love for his mom, dad, sister, grandma, family and girlfriend. It is interesting that he adds his dad to this list, as he had mentioned in the first session that there was no foster dad in his life, only his foster mom.

Table 1: Identifying provisional roles in the session notes

After identifying the different provisional roles, the researcher then went back to the videos to confirm that these were indeed the ones that appeared to be prevalent throughout the sessions. This was to ensure that the researcher had not misinterpreted or missed anything of importance that may have been happening in the music therapy process. Once these provisional roles were confirmed, they were formalised as shown in Table 2:

Colour	Role Type	Characteristics mentioned in the session notes
Red	"The Red Devil"	Overpowering, "naughty", rule-breaker
Yellow	Guarded	Concrete, distance, limited, defence, coping mechanism, lack of depth, lack of emotional sharing
Green	Mastery	Experimenting, learning, determined, aspiration, investment, agency, playful,

		energy, inquisitive, enjoyment, child-like, resilient
Blue	The Sick Patient	Illness, rules, requirements, structure
Pink	Worker	Responsibilities, chores, hardworking, helpful
Purple	Empath	Caring, kind, sincere, loving, careful, extended range, deeper understanding, emotional intelligence, increased awareness

Table 2: Provisional Role Characteristics

The provisional role of the “Red Devil” was only present in relation to R, therefore, the characteristics associated with this role were words used by R such as “naughty” and “rule-breaker”, and the title itself draws from terminology used by R when referring to himself. These were words R used when describing himself and his friends, calling his friend group “the naughty boys”. Therefore, this role represented R’s ‘rebel’ persona that he initially presented with.

The characteristics highlighted in yellow related to guardedness. This colour was assigned when the participant did not want to share, when they deflected, or showed signs of defences. Their sharing was on a concrete level in that they did not want to share emotional information and there appeared to be a lack of depth in terms of intrapersonal awareness.

Mastery was coloured green. The term refers to the sense of having control over the forces that affect one’s life (Conger et al., 2009). The characteristics grouped together here consisted of engagement and investment, agency and determination. The characteristics in this grouping all represented a choice that the participant made, a choice to be involved and to allow himself to be child-like and playful. These elements reflected those that the participant had control over, and could make a decision about.

The provisional role of the sick patient, coloured in light blue, consisted of characteristics such as withdrawal due to physical manifestations of illness such as overexertion, pain or discomfort, as well as their desire for structure and rules. The provisional role of worker, coloured pink, consisted of characteristics associated with being helpful and hardworking.

Finally, the colour purple was associated with characteristics such as emotional insight, intrapersonal awareness, an apparent need for preservation for life through being careful, and

deeper emotional awareness. These characteristics were grouped together to provisionally form the empath role.

4.3.1 Selecting Video Excerpts

Once the provisional roles had been identified through the session notes (and were confirmed through watching all of the video footage of the sessions), the specific video excerpts were selected. Excerpts were chosen that adequately showed the characteristics of these provisional roles that the participants seemed to present during their music therapy process. This offered a starting point to then explore these roles in more detail, to confirm them, to adjust them, or to allow a more refined identification of roles to emerge.

Due to the unequal amount of sessions that each participant was involved in, it was decided that four excerpts would be selected from R's process, one from T and one from F. These were selected to show moments that were representative of how each individual typically presented in sessions. Within the single video excerpts selected for T and F there seemed to be shifting role characteristics (even in the short period of time captured within each video excerpt). R had taken part in the full eight-week process and excerpts could be selected to explore how he had expressed roles over a longer period of time.

On the basis of the review of session notes and the full viewing of the video data, the provisional roles that were most prominently expressed by F were that of the sick patient, a guarded role and an empath role. The excerpt selected from F's process of two sessions was taken from 04:18 in the session and was 4 minutes and 37 seconds long. This excerpt depicted how he initially reflected an empathic aspect of himself (represented by the text coloured purple in the session notes). F then began coughing in the session and he chose to musically reflect this aspect of himself (represented by the text coloured blue) through an instrumental change. F changed from the big, loud instruments, to the small, soft instruments.

On the basis of the review of session notes and the full viewing of the video data, the provisional roles that were most prominently expressed by T were mastery and empath. The excerpt selected from T's process was 19:41 into the session and was 6 minutes and 24 seconds long. At the start of the excerpt, T had just finished receiving a course of chemotherapy, leaving him in visible pain during the session. Despite this, T appeared determined to participate, finding joy and comfort in making music. T did not conform to the "sick role" as may have been expected. Instead he showed resilience by continuing to play, and agency in leading the session back from silence into improvisation as well as teaching the music therapist the words to his song. At the time this was grouped within the provisional role

of mastery, but later when roles were refined and formalised through the thorough process of analysis this was re-grouped within “resilience” (this analysis process is explained fully in section 4.6).

Finally, four excerpts were chosen from R’s process (named R-1, R-2, R-3 and R-4). On the basis of the review of session notes and the full viewing of video data, the provisional roles that were most prominently expressed by R were initially guarded and defensive (however, through further nuanced analysis that will be explained in section 4.6 the roles of resilience, mastery and the empath became increasingly prominent).

The first excerpt (R-1) was selected from the first session with R. It was taken from 20:39 into the session and was 5 minutes and 15 seconds long. This excerpt was chosen as it best represents the role of being guarded and distant. In this excerpt, R was asked to draw a picture of himself. He drew a black and white drawing of a smiling boy who was walking. While the picture of the boy may have been smiling there was enough evidence in the remainder of the situation to link this to being guarded and defensive. Through the discussion R removed himself from his drawing, speaking about himself in the third person. His picture had no colour and it was relatively empty. He spoke at a concrete level, physically explaining what the boy in the picture was doing, as opposed to exploring any emotional content.

R-2 was selected from the third session with R; the excerpt was taken from 00:22 into the session and was 3 minutes and 47 seconds long. This excerpt began with an improvisation in which R seemed distracted, which was typical of his participation in sessions (possibly due to his ADHD). This element of distraction was incorporated into the improvisation that became confident, loud and rhythmical, yet overpowering. This improvisation was then followed by a discussion on how R views himself, the characteristics R describes fell under the role of worker.

R-3 was taken from the seventh session with R. It was 15:24 into the session and the excerpt was 4 minutes and 55 seconds long. This excerpt depicted a moment in an improvisation where R was confident and empathic in his playing, a representation of the empathic role. In the discussion section of the excerpt it shows R letting down his defences, moving away from the guarded role and into the empathic role, demonstrating increased awareness and emotional insight.

R-4 was selected from the eighth session with R. It was 14:45 into the session and the excerpt was 5 minutes and 4 seconds long. This excerpt musically represented R’s emotional investment in the music therapy process. Beginning in his role of the “Red Devil”, a social

identity he shared with his group of friends, he then shifted to his role of empath as a careful person who has preservation for life and increased intrapersonal awareness.

Once the excerpts were selected, rich, thick descriptions were written (see Appendix F for full thick descriptions of the excerpts). Two composed songs were included in the analysis process in addition to the excerpts. While song-writing was initially an integral part of the research process for each participant, it was a component that only featured in the process of R. The first song and the last song written by R were transcribed verbatim and incorporated into the coding process (see Appendix F for the transcriptions of the lyrics).

4.4 Coding

Braun and Clarke (2006) state that the first phase in thematic analysis is to familiarise oneself with the data. This was done through the session note review, selection of appropriate excerpts, and through reading all the thick descriptions and transcriptions of the lyrics. The second phase is to generate initial codes that identify a feature of the data that is relevant to the research question and refers to an element of the raw data that can be assessed in a meaningful way.

In preparation for coding, the thick descriptions were sorted into meaning units through the use of square brackets, which can be seen in the first column in Table 3. The meaning units that were relevant to the research question, indicating characteristics of roles that the participants were fulfilling, were then coded. This can be seen in the second column in Table 3 (see Appendix G for the full list meaning units and coding). Through the coding process a total of 449 codes were generated (see Appendix H).

<p>[R immediately responds, confidently at first] [but then he has to think and he pauses, “I like to be...um, how do you explain it...I like to be like, uh...no one must judge him, he just want to be him.”] [As I write this down R stares at my hand intensely.] [“No one must judge him” I say in confirmation as I write it down. I look up at R and he nods at me casually and in affirmation. “Cool!” I say and</p>	<p>A50- confident A51- deeper emotional sharing A52- serious A53- casual agreement</p>
--	---

<p>R casually nods at me and I nod at him, in acknowledgement of what we have written together and what R has shared with me. "Let's play some drums" I say to R and he gently nods in agreement,] [looking protective, on guard in his body language and facial expression.]</p>	<p>A54- defensive and on guard</p>
<p>[T smiles and looks at me as I sing, continuing to strum.] [I repeat my melody, in hopes T will catch on to it and sing], [and at the third repetition T adds his voice.] [His voice is soft and raspy but present.] [T continues to play and sing, smiling as he does so and moving his head gently down with each main beat we play.] [We make eye contact and smile at one another as we sing the same melody.] [I then interchange between singing the original motif and then a short variation and back to the original motif.] [This makes T smile even more and he follows, continuing to sing.]</p>	<p>E21- showing awareness of others E22- agency in singing E23- soft but present vocal E24- enjoyment and engagement with the music E25- personal interaction E26- increasing awareness of others</p>

Table 3: Coding

Table 4 illustrates the coding process of the first and final song written by R.

<p>R Song 1</p>	<p>Codes</p>
<p>[We must care for one another]</p>	<p>G1- caring</p>
<p>[Love one another]</p>	<p>G2- love for others</p>
<p>[We must keep on dreaming]</p>	<p>G3- encouragement and determination</p>
<p>[Your dreams will one day come true]</p>	<p>G4- hope</p>
<p>[Red devil] [wants to be himself]</p>	<p>G5- distancing</p>
	<p>G6- wants to be himself</p>

<p>[Nobody must judge] [me]</p> <p>[I wanna judge myself]</p> <p>[If you know what I mean]</p> <p>[You must love your family</p> <p>You must love them more than anything in this world]</p> <p>[You must love your sister more</p> <p>Cause she is your blood]</p> <p>[If you know what I mean</p> <p>Yeah, Yeah</p> <p>If you know what I mean</p> <p>Yeah, Yeah]</p>	<p>G7- defensive</p> <p>G8- personalisation</p> <p>G9- judgement</p> <p>G10- relating</p> <p>G11- love for family</p> <p>G12- deeper affection for blood relative</p> <p>G13- relating</p>
<p>R Song 3</p>	
<p>[I'm handsome,]</p> <p>[I care]</p> <p>[I love, Sometimes I'm moody, yeah]</p> <p>[I like to work and help out]</p> <p>[I like to play]</p> <p>[I don't like people who are boring]</p> <p>[I don't like people whose moody]</p> <p>[I wish I could change my illness]</p> <p>[I don't like it]</p> <p>[I want to do what others can do]</p>	<p>H1- confident</p> <p>H2- caring</p> <p>H3- deeper emotional awareness</p> <p>H4- helpful</p> <p>H5- playful, child-like</p> <p>H6- disinterest in boring</p> <p>H7- assertive in dislikes</p> <p>H8- preservation for life</p> <p>H9- resentment</p> <p>H10- desire</p>

[But I can't]	H11- helpless
[I don't like it]	H12- resentment
[But I want to want to change it	H13- preservation for life
Oh yeah,]	
[And be good and strong]	H14- desire to be healthy

Table 4: Songs Composed by R

4.5 Developing Categories

According to Braun and Clarke (2006) the next phase in the analysis process is to search for themes. This study did this by utilising a coding hierarchy as suggested by Gibbs (2007). A coding hierarchy is a method of grouping codes into branches in a hierarchical system. The coding hierarchy, organises the data in an ordered format (as the analysis process may generate large numbers of codes), can constitute a form of analysis in itself, prevents duplication of codes, and provides clear analysis (Gibbs, 2007) (see Appendix I for the coding hierarchy).

This process was useful for the current study as it provided a layout that was organised and clear to assist in generating categories. Through the coding hierarchy fourteen categories were developed. These categories included:

- | | |
|---------------------------|-----------------------------|
| Guarded and Defensive | Confidence |
| Physical illness | Strong and powerful |
| Unsure and reserved | Determination |
| Agency | Therapeutic alliance |
| Engagement and investment | Reciprocity |
| Experimenting | Emotional insight |
| Child-like | Awareness (inter and intra) |

While provisional roles were identified at the start, the full analytic process of coding and categorising the data enabled the researcher to gain a more nuanced understanding of the

expression of these roles and how participants were able to explore them and potentially shift in how they expressed them.

4.6 Themes

The next phase in the data analysis process entailed developing themes (as discussed by Braun & Clarke, 2006). This involved grouping the categories together within the format of a hierarchy. This tidy format allowed the relationships between categories and themes to be more easily identified (Gibbs, 2007). The colour system was retained.

By defining and refining the researcher is capturing the essence of the theme, not simply paraphrasing but rather encompassing the story they tell (Braun & Clarke, 2006). Three of the themes were termed “role palettes”. This was because they were considered as slightly more multifaceted than a singular unitary role. Each palette contained a range of related role behaviours. During the music therapy sessions, the participants seemed to move between these role palettes. The fourth theme related to the therapeutic relationship. The themes are presented below in the format of a hierarchy for convenience and consistency, as can be seen in Figure 1. The format of a hierarchy in this regard demonstrates how the categories were grouped into the themes. After this figure brief descriptions of each theme are provided. They are then discussed in detail in the following chapter.

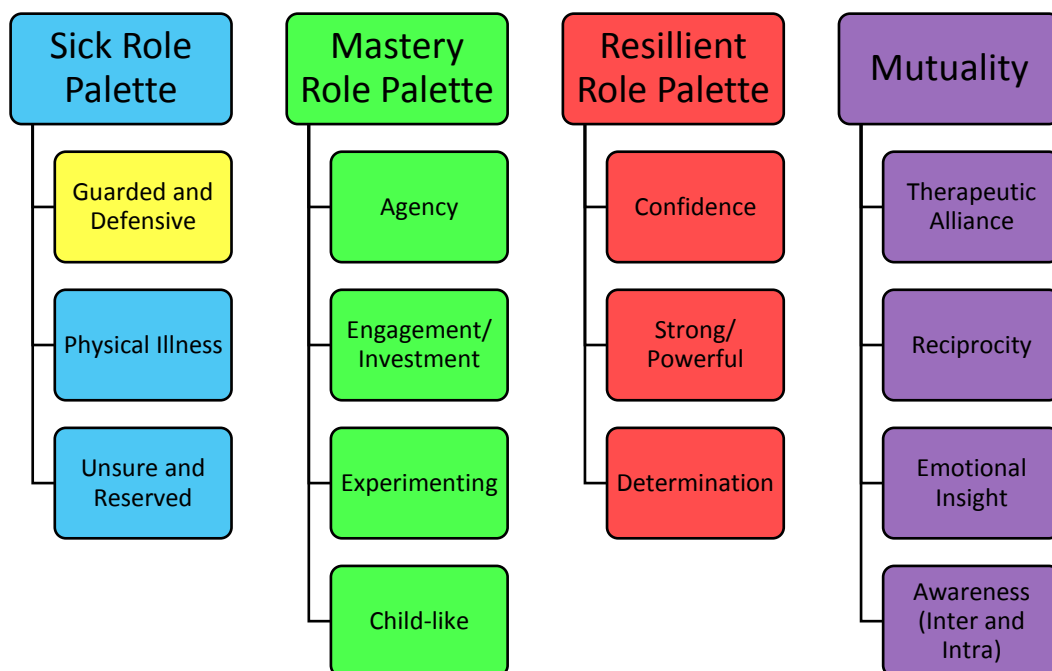


Figure 1: The Four Themes

4.6.1 Theme 1: Sick Role Palette

Present in every participant's first session, this palette comprised characteristics associated with being guarded, defensive, uncertain and reserved, as well as moments in the therapy process when the physical aspects of the illness seem to cause the participant to withdraw in some way.

This palette is theoretically related to Parson's (1978) conceptualisation of the "sick role". The concept of the "sick role" is one in which patients take on this identity of a patient, relinquishing responsibility and identifying mainly with aspects of their illness. In 2012, O'Callaghan and colleagues investigated the use of music therapy in paediatric palliative care, in assisting children in reintegrating a healthy self-image with their patient identity. It is from this that the research has drawn the name of "sick role" for this palette.

In the current study qualities of, for example, guardedness and defensiveness may have been related to unfamiliarity of the music therapist, the therapy space, as well as possible uncertainty regarding what to expect, the research process and the new client-therapist relationship. However, in light of the above described role that patients can assume it is argued that these characteristics can be affiliated with this category. This will be explained further in the following chapter.

Physical Illness was placed with *Guarded and Defensive*, and *Unsure and Reserved*, as this category contains codes which refer to the pain and discomfort experienced by the participant, causing them to withdraw from the musical or personal interaction. This was unlike *Resilience*, in which the pain or discomfort was evident but the participant did not withdraw instead showing agency and determination in wanting to musically engage despite the physical presence of the illness.

4.6.2 Theme 2: Mastery Role Palette

The characteristics situated within this palette included; experimenting, investment, engagement, variation, agency, as well as being child-like. *Child-like* was categorised under the role palette of *Mastery* as the codes within included curiosity, creativity, excitement and contemplative. These were characteristics that fitted within the definition of mastery in this study due to their relationship with their capacity to make choices (as discussed by Conger et al., 2009). As such, these characteristics were seen as being related to *Engagement and Investment*, *Experimenting and Variation* and *Agency*.

Within this willingness to explore, to play and to engage, appeared to come an investment not only in the music, but in the music therapy process. Due to the nature of the characteristics and categories situated within this palette, it represented aspects in which the participants seemed to show control over even a few of the forces that affected their lives and was therefore named *Mastery*.

4.6.3 Theme 3: Resilient Role Palette

The characteristics associated with this palette were present in every participant. This palette represents the strength presented by the participants. In particular, this was reflected within the music they created. The qualities of their playing and music-making demonstrated their internal strength and power despite their illnesses. This palette consisted of the categories *Confidence, Strong and Powerful, and Determination*.

Through this process the characteristics originally associated with the provisional role “Red Devil” (coloured red) took on a new meaning. Instead of indicating a role where confidence was characterised by being overpowering and “naughty”, features such as strength and power emerged more prominently. As such, through the more detailed thematic and comparative analysis these characteristics were grouped rather within a role of resilience.

4.6.4 Theme 4: Mutuality

This theme emerged later in the process for R, but was present in the process with T. The categories situated in this theme are *Therapeutic Alliance, Reciprocity, Emotional Insight and Awareness (inter and intra)*. Within the client-therapist relationship the participants became comfortable with the music therapist, were able to demonstrate emotional insight, to share these emotions with the music therapist, and to reach a point of reciprocity.

This theme consisted of characteristics that demonstrated deeper emotional awareness, vulnerability and willingness to enter into a therapeutic relationship. Through this willingness and engagement, they appeared to develop the quality of a reciprocal client-therapist relationship, namely the therapeutic alliance.

4.7 Conclusion

This chapter described the data analysis process and presented the findings. A brief description of each participant was presented followed by a detailed description of how the particular excerpts were selected for thick description (through the review of session notes using colours relating to specific characteristics of provisional roles). The section that followed illustrated how the codes were generated and, using a coding hierarchy, were grouped together and categorised. These categories were then grouped together into themes. The final section of this chapter provided a description of each theme. The following chapter presents a further discussion of the themes with reference to the literature.

Chapter Five: Discussion

5.1 Introduction

This chapter will discuss the themes that were identified through the analysis process, in relation to the research question. The findings will be integrated into the literature discussed in chapter two.

5.2 The Sick Role Palette

According to Linebarger et al. (2014), life-limiting illnesses evoke challenges for adolescents in the areas of physical development, autonomy, identity, cognition and spirituality. Adolescents face an identity paradox as they try to reconcile their previously known self with their 'sick identity'. This paradox can be seen when some individuals become defined by their illness, and their identity shifts to the role of "patient" rather than the role of "a teenager who is suffering from an illness". In this study, each participant seemed to show characteristics from the sick role palette at some point in the initial phases of their processes, especially being defensive and guarded.

As this was a new experience for them, it was not uncommon for these types of characteristics to be present. However, the characteristics presented as more than simple unfamiliarity. Parson's (1978 in Bradley et al., 2011) conceptualisation of "sick role" is one where clients take on this identity of a patient. O'Callaghan et al. (2012) worked with assisting children in paediatric palliative care to reintegrate healthy self-image with their patient identity.

In particular, F demonstrated a moment where he musically withdrew due to discomfort caused by overexertion. In this instance, he appeared to be situated in this role palette due to the physical boundaries caused by his illness, which he seemed unable to overcome at the time. Due to the severity of his illness these boundaries presented as lack of movement caused by a decline in strength, decreased ability in, and range of, motion and a general lack of energy. These boundaries were noted in the following session and so, in order to meet the physical and emotional needs of F, as his music therapist I drew on more receptive music therapy techniques rather than the active improvisation and song-writing that the research process initially emphasised. As the music therapist, I needed to demonstrate flexibility when meeting the individual needs of the participants, despite the needs of myself as the researcher. The ethical principles of non-maleficence and beneficence were present in this situation. This

was an important consideration that resulted in adjusting the mode of music therapy techniques in the process with F.

All three participants had been in palliative care for an extended period of time, some for years, and it seemed as if they had adopted particular characteristics of a patient role within their identity. F, for example, had been in palliative care for a number of years. His physical presentation could be associated with the role of a patient due to the length of time he had been in this environment as he was guarded, reserved, defensive and made minimal motion. R's presentation in the first three sessions in particular was mainly comprised of characteristics associated with this role palette.

His personal interactions appeared to remain on a concrete level, as he deflected any opportunity for vulnerability and distanced himself when needing to share personal information (for example, referring to himself in the third person). However, the lyrics composed in his first song reflected concern about others' views of him and also his concern for the wellbeing of others. It would appear that while R was guarded and defensive in verbal interaction without musical framing, he was able to express his concerns through a musical format. Having psychosocial concerns, according to Zebrack and Isaacson (2012), is part of a healthy emotional development of an adolescent, and psychosocial support is imperative to the quality of life of an adolescent in paediatric palliative care (Freyer, 2011).

The role of the palliative care clinician, in this case the music therapist, is to assist the patient in their journey along the quality of life continuum (Liben, 2007). In the case study of F, this was crucial for the majority of the process as the role of music therapist was to assist in easing his pain and suffering.

Suffering could be viewed as part of the sick role palette, as it can entail a threat to an individual's personhood (Liben, 2007). Personhood refers to how a person is seen and responded to by others. It is a status that arises from relationships and the context of social situations, reflecting the degree to which a person has perceived social value and how this changes over time (Turnbull III, 2014). In this context, it would seem as if the physical illness is that which is threatening F's personhood, and, possibly, the suffering of the loss of life as yet un-lived.

Foster et al. (2010) state that the aim of paediatric palliative care is to enhance life, decrease suffering and aid in personal and spiritual growth. Paediatric palliative care is the active total care of the child's body, mind and spirit, as well as the provision of support to the family. Palliative care aims to improve the quality of life through the prevention and relief of suffering,

which is achieved through treatment of pain and other problem areas, whether these are physical, spiritual or psychosocial (Liben et al., 2007).

While the aim of palliative care is to improve the quality of life, a terminal illness may impact the rate of development of an adolescent. This may influence areas of maturation, social, emotional, and cognitive development, or even physical growth through hormonal changes (Linebarger et al., 2014). There may be a period of accelerated growth (as seen, for example, in T's more advanced emotional and cognitive developmental level in his musicality, leadership and empathy), or it may have a negative impact in terms of social developmental delay (for example, as in the case of F, who relied heavily on his mother).

All the participants responded in their own manner when confronted with their illness and how this was incorporated into their identity. F seemed to have embodied the role of patient, while T appeared to use this status as motivation and encouragement. This was seen in the empathic manner in which T led the music in his first session, introducing a new song and being relationally sensitive in his manner of musical communication.

5.3 The Mastery Role Palette

It appeared to be within the palette of mastery that the participants explored their identity. This may be seen in an example with F, in which he explored the different instruments, playing a wide variety, investigating the different sounds until he chose the instruments of the drum and snare. In this example, F appeared to be demonstrating characteristics associated with the mastery role palette—experimenting, exploring and engaging—until he found instruments he was satisfied with to adequately represent him.

Music therapy has been used in the development of identity as it provides a potential space in which creativity can be explored (Daykin et al., 2007). It is in this space where the role palette of mastery could be developed as music therapy appeared to provide a potential space where participants could experiment, engage with the music and develop agency and investment in the music therapy process. This music therapy process and the potential space it provided may have been the catalyst in a process of shifting role palettes. An example of this can be seen in R's shift from the sick role palette to the mastery role palette within the music therapy process.

This potential space where creativity could be explored may have been beneficial in the restoration of pre-illness identity, creation of new roles, relief of suffering, empowerment and helping to find meaning in this challenging situation (Daykin et al., 2007). This can be seen in

an example with R in which he took hold of the opportunity for self-exploration, particularly in relation to his composed songs. Through experimentation within the music and lyrics he appeared to demonstrate deeper emotional insight and awareness.

Being involved in making choices is an invaluable and enriching aspect of the music therapy process for patients in palliative care (Daykin et al., 2007). Having choices (such as during improvisation, song-writing, listening to pre-composed music etc.) facilitated expressions of agency from all the participants. T, for example, showed agency when he began singing a religious song and then stopped the music and taught the music therapist the words. He was adamant that the words should be correct. In music therapy he took hold of opportunities for choice and leadership.

5.4 The Resilient Role and Personal Growth

In the face of a life-limiting diagnosis, adolescents experience a challenge to their normal order of life and their expectations of how life should work. Although the uncertainty of the future associated with terminal illness can be cause for distress, it can also be a catalyst for personal growth, a deeper appreciation for life, greater awareness for the purpose of life, as well as development of confidence, resilience and optimism (Zebrack & Isaacson, 2012).

Confidence and determination are two of the categories associated with the resilient role palette in this study. Each participant demonstrated characteristics from this role palette in their music therapy process. In the case study of R, for example, this appeared evident through the qualities of the music-making process, his confidence in leading the sessions, and his participation in the song-writing process. In the lyrics, his confidence in himself was apparent, which can be seen in the lyrics "I'm handsome, I care, I love, Sometimes I'm moody, yeah, I like to work and help out, I like to play". There also appeared to be a shift in his greater awareness for the purpose of life, and appreciation for life, which can be demonstrated by the lyrics "I wish I could change my illness, I don't like it, But I want to change it".

In the case of T, resilience was shown in his music-making process. Despite having received a course of painful chemotherapy, he continued to play the guitar with confidence, pushing through the pain so as to creatively express himself. Again, in the case of F this resilience and confidence was shown in the strong, powerful, loud and lively music he created. He chose loud instruments to play to better appropriate himself musically.

Daykin et al. (2007) state that music therapy provides adolescents in palliative care opportunities for power, freedom and release, in contrast to the lack of power experienced in

relation to their illness. All three participants appeared to demonstrate resilience and power in the face of their illness. For example, F was overwhelmed by pain in his musical improvisation, causing him to withdraw, but he maintained hold of his instrument throughout. His body may not have been able to continue playing, but this did not cause him to easily relinquish the instruments, or his right to play. In an improvisation with R during his third song, there was a section where he appeared to be unable to sing the words due to the nature of the content regarding his desire to change his illness. However, this did not stop him from musically participating. R demonstrated confidence, strength and power in his drumming, despite not being able to physically sing the words. Music therapy provided these participants the opportunity to express their confidence, strength and power. Music therapy afforded the space to recognise the strength within, to explore this and to acknowledge it, perhaps incorporating it into their role identities.

Experiences of choice and enrichment provided by music therapy are contrasted with the limitation, isolation, disempowerment and restriction experienced by patients in palliative care (Daykin et al., 2007). It appeared that, through the opportunities for choice of musical elements as well as the creative possibilities of the potential space provided by music therapy, this exploration of strength, power and individuality could have occurred. This occurrence may have facilitated the emergence of characteristics associated with the mastery and resilient role palettes, such as agency, experimentation, engagement, confidence, strength, power and resilience.

5.5 Shifting between Role Palettes

Throughout the music therapy process it seemed as if the participants moved between role palettes, shifting from the sick role palette to those of mastery and resilience. There appeared to be a distinct change from the one to the other, particularly for R. However, there was also an overlapping of these role palettes at times. Stryker and Burke (2010) highlight that a person does not encompass one role alone, but rather builds their identification of self through a hierarchy of role identities. This also contributed to the reasoning behind the use of the term role palettes rather than specific roles.

Marcia (1980) states that identity is a dynamic concept and, therefore, it is not unlikely that a shift would be apparent. Also, a sick adolescent still has the potential to be resilient and it appeared that music therapy offered them the opportunity to express that. This could be the justification for the overlapping in role palettes.

Amir (2012) states that music can play a vital role in formulating, developing and expressing individual identities. This is possible as it provides a means to share emotions, meanings and intentions, as well as to elicit deep and profound emotions within us. As discussed in the literature review, according to Erikson's theory of identity, identity development continues throughout the lifespan. However, it is most impressionable in the early stages, and this continues into adolescence (Marks et al., 2002; Erikson, 1994). Marcia (1980) states that identity does not begin and end with adolescence but rather that adolescence is a transition period. This is particularly so regarding the shift from one's psychosocial concerns based on other's expectations to a focus on one's own unique organisations of beliefs, history, shortcomings, skills and goals.

Notably, adolescence is a time where physical development, cognitive skills and social expectations coincide (Marcia, 1980). This enables adolescents to sort through and synthesise their childhood identifications in order to construct viable pathways towards adulthood (Marcia, 1980), or in the case of these three participants to find meaning in the end stages of their lives.

The role a person identifies with is most likely to change depending on the situation. In the initial phase of the music therapy process R would show characteristics of being guarded and defensive in verbal interaction (characteristics affiliated with the sick role palette). However, when confronted with a different situation through the composition of a song, R showed characteristics of engagement, investment, and interpersonal awareness, seeming to demonstrate psychosocial concerns through his lyrics. In this example different situations (a verbal conversation compared to the musical frame of composing song lyrics) elicited different role palettes as expressed by R.

In R's process, the model of identity discovery as noted by Forrest (2001) appeared to be relevant. Forrest viewed music as a useful medium to discover identity on three inter-related levels. The first of these is a social level where music can be used to explore culture, social boundaries and social contexts. Secondly, music can be used as a tool to develop personal identity; the music allows a safe space to test boundaries, hierarchies and further develop identities. The third level is where music may define identity historically by reminding the participant of events passed.

R began at the first level of exploration of social boundaries and contexts by testing the boundaries of the music therapy space within his improvisations. The first level may be reflected by the characteristics associated with the mastery role palette in which R was

exploring the music therapy space, the client-therapist relationship and showing signs of engagement and investment. In the second level he used music as a tool to develop his personal identity (as seen in the lyrics of his composed songs). This second level may be reflected by characteristics associated with the mutuality palette (which will be discussed momentarily) in which R appeared to demonstrate deeper emotional insight and intrapersonal awareness.

The shift in role palettes may be sudden or gradual. In the case of F, it appeared to be sudden, within the timeframe of ten minutes. His general presentation in the music fell within the resilient role palette; he was confident, rhythmical, strong and determined. However, when discomfort and pain were evident he withdrew musically and personally. He avoided eye contact and seemed to be defensive and guarded. Despite the shift between these roles, his resilience remained as he continued to hold onto the instruments, despite not being able to physically play at that moment.

In the music situation, F appeared to identify with the resilient role palette, but in the hospital situation where illness was prevalent, he identified with the sick role palette. Perhaps, in his role hierarchy, his resilient role identification took preference in the music situation, until his illness became overpowering and took preference. This can be justified through identity salience, as noted by Stryker and Burke (2010). The probability is that an identity will be provoked according to the situation, in this case the overwhelming prevalence of physical symptoms.

Shifting between role palettes may take a lengthier period, over the course of six weeks, such as in the case of R. R appeared to show characteristics of guarded, defensive and reserved for the first three weeks of the process. However, this role palette seemed to overlap with the resilient role palette as he seemed to show moments of confidence and strength in his music. It was through the exploration of the mastery role palette, through experimenting, engagement, investment and agency, that R appeared to demonstrate characteristics associated with the palette of mutuality. It may have been due to the exploration of agency and investment in the music therapy process that reciprocity, emotional insight and the therapeutic alliance developed.

5.6 Mutuality and its Potential Role in Transformation

Music therapy provides an opportunity for intimacy within a creative, equal and non-judgemental relationship. Within this relationship, the patient is encouraged to explore identity

creatively in light of illness (Aldridge, 1995). In the current study it seemed that once the client-therapist relationship had met a point of mutuality that a transformation of role identities was possible.

Evaluating the nature of the client-therapist relationship proved of value in determining if there may have been a shift in role palettes. According to Wigram (2002) there are various methods one can use to evaluate the process of music therapy. These include assessing the nature of the client-therapist relationship; the client's personal experience of the music therapy; the therapist's personal experience of the music therapy; changing quality of music in the dynamic interaction over time; and perception of others regarding the process of music therapy. Through assessing the nature of the client-therapist relationship in the current study the music therapist was able to evaluate the music therapy process. This was possible through the observation of characteristics demonstrated by the participants' behaviour in relation to the music therapist. Through this it was then able to identify if any shifts had been noted.

Through R's process the researcher observed expressions of different behaviours over time that may have indicated that more of a shift occurred. The nature of the client-therapist relationship changed from being distant to being one of reciprocity and mutuality. This was observed through the musical interaction, personal interaction and the characteristics demonstrated by R. In the beginning of his process, R appeared to show characteristics associated with the sick role palette. As mentioned, he seemed guarded, defensive and reserved for the first three sessions in the music therapy process. This is not uncommon in the early stages of therapy and therefore these characteristics may be associated with the sick-role palette, however these may also be associated with the beginning of a therapeutic relationship. Through the exploration of the musical space, testing of boundaries and a growth in emotional insight, as seen in the improvisation and composed songs, the client-therapist relationship seemed to shift to a point of mutuality and reciprocity. An example of this can be seen in the final excerpt when R struggles to sing an aspect of the song and relied on the music therapist to vocally carry the section while R drove the music through his drumming. In this moment there appeared to be a moment of reciprocity, of give and take and of mutuality.

Along with the possible shift in the client-therapist relationship, R appeared to demonstrate differing characteristics throughout the music therapy process. Through the composition of songs R appeared to show an increase in interpersonal and intrapersonal awareness. His concerns seemed to change from that of others opinions of himself, such as "nobody must judge me", to his own opinions of himself, "I'm handsome, I care...I wish I could change my illness". These differences may be seen as a shift of role palettes, from the sick role palette in which he demonstrated characteristics of guarded, defensive, reserved, and concern for

others' opinions of himself, to that of mutuality in which he demonstrated characteristics of emotional insight, reciprocity and increased intrapersonal awareness.

This possible shift may also be demonstrated in the lyrics of R's first song in which he referred to himself as the *Red Devil*. In his song, he spoke to "others" about what they should be doing in the world, how he wanted to be treated by others and how others should have hope. R was distancing himself from the song's content by referring to himself in third person as the *Red Devil* and by focusing on others. This may be seen as a defence against focusing on his own feelings. He appeared to be demonstrating characteristics of being guarded and defensive. However, by then focusing on how he wanted to be treated R appeared to demonstrate his own feelings, showing intrapersonal awareness, but this is still linked to an external source of "others" and how the "others" were to treat him. This song was written in R's first music therapy session and it would appear that an increase in interpersonal awareness can be seen from this first song to the final song.

In his final song R seemed to show more concern for himself than for other's opinions of him, as was prevalent in the first song. Now R spoke of himself through his lyrics in the first person, the song was named after him and he showed greater personal investment in this song. The lyrics demonstrated emotional insight, deeper awareness and a broader range of expression. R spoke of his illness, an aspect that was challenging to breach, and of his desire to not be ill, to be like others and to change his illness. His opinion seemed to alter from what others thought of him to wanting to be healthy like them.

It would appear that this level of awareness, and emotional exploration became possible through the mutuality and therapeutic alliance that developed between client and therapist through the music therapy process. That is not to say that F and T did not demonstrate any shift, or transformation, as they did. However, the transformation of R appeared to be the most distinct through a transition over a greater period of time.

5.7 The Function of Music Therapy

This research study aimed to understand the function of music therapy in the transformation of role identities for clients who had been in paediatric palliative care for an extended period of time. The goal of music therapy was to facilitate a transformation of identity through allowing the exploration of different role palettes. Through the safe space of exploration provided by music therapy it seemed that the participants were provided opportunities for creative self-expression and identity development.

Music therapy can play a vital role in the formulation, development and expression of identities (Amir, 2012). In the current study music therapy may have contributed to the possibility of participants shifting between role palettes. For example, this may be seen in a moment of improvisation with T during which he showed confidence in his musical qualities and agency in leading the music, while earlier he had been quiet and shy; when F showed resilience in holding onto the instrument despite his physical illness causing him to withdraw; and where R showed confidence and resilience in the composing of song lyrics and, at the same time, deeper emotional insight and intrapersonal awareness, while earlier he had been guarded and defensive.

An identity is salient and consists of many roles, provoked according to the current situation (Stryker & Burke, 2010), and music may be used to anchor and frame these situations (Ruud, 1997). F's music was loud, lively, strong and powerful and particular characteristics of the resilient role palette seemed to be evident. This was until F became overexerted and discomfort was visible. In this different situation, roles associated, and characteristics related, to the sick role palette were evoked and the music became silence. This example demonstrates the musical appearance of different role identities, or characteristics, induced by different situations.

Music therapy can be utilised as a safe haven for internalising a healthy self-image alongside patient identity. Music can be used as a transitional space, that holds and nurtures while supporting the exploration of new realities. Adolescents' perception of themselves can shift due to their 'non-illness' identity being acknowledged (O'Callaghan & Barry, 2010). Acknowledgement of participants' "non-illness" identity may function as a catalyst for a shift in characteristics and role palettes. Opportunities were created for this in the current study through, for example, providing the participants with choice within the music therapy process (choice of instruments, choice of improvisation or song-writing, choice of expression).

Song-writing was a valuable tool in R's music therapy process. This was an element that was requested frequently by R in his sessions. Song-writing is a powerful technique in the field of palliative care. It facilitates the expression of suppressed feelings, instils feelings of contribution to the world, and provides the client pleasure, contributing to self-efficacy. Song-writing assists clients in the expression of their feelings, and enables discussion between the clients and their families (Clements-Cortes, 2016). For example, in R's music therapy process and the composition of his final song, R was able to acknowledge and express internal desires, desires to change his illness, desires for his future and preservation of his life. This deeper emotional insight, and ability to access these suppressed feelings, was made possible for R through the process of song-writing.

The material from the composed songs was incorporated as the basis of improvisation in R's sessions. It was in these improvisations where R could fully musically express the lyrics he had written. Clinical improvisation benefits a release and resolution of painful feelings; assists the client in building a therapeutic relationship with the therapist, assisting the client in feeling understood; helps the client to access and then process unconscious issues and emotions; and assists in increasing comfort and decreasing anxiety (Clements-Cortes, 2016). It was through improvisation that R was provided the opportunity to release painful feelings through the lyrics he had written. He also could play loud music with strength, power and a driving force. It was through the combined use of song-writing and improvisation that R was afforded the opportunity to fully express himself and explore different role identities. It may have been this opportunity and process that facilitated the change in characteristics, and role palettes, of R.

The therapeutic alliance seemed to be evident in the final improvisation of the last song composed by R. There was an instant in which the lyrics conveyed difficult emotions and R vocally withdrew, relying on the therapist to sing the lyrics. This did not appear to denote a lack of investment or isolation, as he continued to play the instrument with intensity and power, but rather a trust in the therapist to express an aspect of music which may have been too difficult for him to express personally. This is an example of one of the functions of the therapeutic alliance and how there was reciprocity in the client-therapist relationship.

5.8 The Value of Music Therapy in Palliative Care

This research process has highlighted a need for interventions of this nature in the palliative care setting. The value of music therapy was noted by staff at the hospital who reported witnessing positive changes regarding the behavioural and emotional presentations of the patient-participants, particularly in the presentation of R.

There is a general lack of paediatric palliative care treatment in South Africa, which was noted in a survey conducted by Connor et al. in 2014. This type of medical treatment is a human right according to Gwyther (2014), as it is an appropriate and compassionate response to the needs of patients suffering from a life-limiting illness.

Yet, there are barriers to its development in South Africa. These include lack of education, lack of awareness, lack of integration and fear of opioid use (Connor et al., 2014). These barriers in paediatric palliative care make it difficult for music therapy to be incorporated into the setting due to the lack of palliative care programs. It is the lack of programs that is the

priority focus in advocacy for palliative care in South Africa at the moment. However, I argue that music therapy should also be specifically advocated for in this environment.

Music therapy has many benefits in the palliative care setting, which are achievable through various techniques, such as receptive, creative, re-creative and combined techniques (Clements-Cortes, 2016). The use of music listening, song-writing and improvisation appeared valuable for each of the participants in this research study and seemed to contribute towards the relief of suffering and the enhancement of these participants' quality of life, which is the overall aim of palliative care according to Foster et al. (2010). This study found that creative techniques appear to be powerful and useful, especially as evidenced in the process with R.

The use of receptive techniques seemed to be of value particularly in F's second and final session. The receptive techniques that have been shown to be of benefit in palliative care include music listening and guided imagery according to Clement-Cortes (2016). A study conducted by Hilliard (2005) found that the use of music listening resulted in reduced perception of pain, and increased feelings of relaxation, physical comfort and contentment, which appeared to be the case in F's final session. F was not able to actively participate and instead requested to receive receptive music therapy. Through the use of guided relaxation and imagery he became visibly more relaxed. The use of receptive and active music therapy seemed to be of value in the process with all the participants.

Many potential positive changes were noted in the participants, particularly R, such as enhanced mood and increased expression of feelings, which according to Clements-Cortes (2016) are a few of the benefits associated with creative techniques in music therapy. This was seen through the range of feelings expressed by R in the composition of his songs; through the confidence T demonstrated in leading the music therapy session; and in the music improvisation of F. In particular, singing appeared to assist in increasing a perceived sense of self-awareness, boosting confidence, assisting in emotional release, and stimulating reminiscence, and this was noticeable in the music therapy process with R. Through the composition of songs and the singing of songs, R appeared to demonstrate emotional release, emotional insight and self-awareness as well as an increase in confidence.

Music therapy is becoming an increasingly common practice within the holistic care of a person at end-of-life around the globe, particularly in the United States of America and Europe, (Clements-Cortes, 2016). However, it is not common practice in South Africa or Sub-Saharan Africa. The current study highlights the need for the use of music therapy in palliative care wards, as well as the need for music therapy to be integrated into the interdisciplinary teams in South African palliative care wards. Although there are music therapists working in palliative care wards in South Africa, this number is infinitesimally small as is the number of palliative

care wards. There is a general lack of palliative care wards in South Africa, despite the efforts to increase this (Connor et al., 2014; Gwyther, 2014).

5.9 Conclusion

The main research question guiding this research study was:

What is the function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time?

The aim of the study was to explore this potential function of music therapy in the transformation of role identities for adolescents, to examine the value music therapy can have for patients in this critical stage of their lives, due to their illness, and to explore whether music therapy should be encouraged in palliative care wards in South Africa.

In the initial phase of the music therapy process each participant seemed to demonstrate characteristics associated with the sick role palette (being guarded, defensive, sharing in a concrete, reserved and unsure). It is important to note that in the case of one participant there was a process, however for the other two participants observations regarding a shift in roles were based on selected moments taken from one and two sessions respectively. As the process continued, music therapy appeared to provide the potential space in which the participants could explore their identity, as well as issues that are prevalent amongst children in palliative care (such as those revolving around identity and autonomy).

Throughout the music therapy process, the participants appeared to demonstrate a shift in characteristics associated with the sick role palette to those associated with other role palettes, such as confidence, resilience, agency, playfulness, engagement and investment. This may have been an indication of personal growth experienced by the participants through the music therapy process.

These observed changes could have been made possible through the development of the therapeutic alliance, highlighted in the theme of mutuality. The development of this was evident through the change in characteristics demonstrated by the participants. These changes appeared to be from that of guarded and defensive to that of mutuality, reciprocity, deeper emotional insight and awareness. Observation of participants in early sessions showed characteristics associated with the role palettes of mastery and the sick role, while later in sessions they appeared to show characteristics associated with resilience and mutuality. Although methodologically one cannot establish the presence of conclusive change, these descriptive accounts appear to show the potential for some shifts having occurred in the expression of role identities and this deserves to be researched further.

Chapter Six: Conclusion

6.1 Introduction

This chapter will summarise the research findings. This will be followed by a discussion of the limitations of the study and recommendations for future research.

6.2 Summary of the Findings

This research study explored the function of music therapy in the transformation of role identities for adolescents who had been in paediatric palliative care for an extended period of time. The study found that the function of music therapy in this potential transformation was that of facilitator of self-exploration, and as the catalyst for a shift in role expression. This was explored through observation of the apparent change in characteristics demonstrated by the participants. Characteristics of the participants' personal and musical interactions were classified, coded, categorised and then grouped into role palettes; sick role palette, mastery role palette, resilient role palette, and the theme of mutuality.

The characteristics in the initial phase of the music therapy process were largely guarded, defensive, reserved, unsure, concrete, which were classified as being part of the sick role palette. Through the safe space of exploration provided by music therapy the participants appeared to demonstrate differing characteristics that could be associated with other role palettes. Through the examination of these characteristics there appeared to be a shift in role palettes, therefore, possibly a transformation of role identities.

Apart from the primary aim of exploring the value and function of music therapy, the research study found a need for advocacy around the inclusion of music therapy in paediatric palliative care in South Africa. This was argued in relation to the discussion of literature on music therapy in palliative care and feedback received from the staff at the hospital.

6.3 Limitations

There were limitations experienced in this study. The sample size was small as only three participants were available for inclusion. It was challenging to ensure full music therapy processes for all participants, as initially required by the planned methodology, as two participants passed away after receiving a limited number of sessions. Of the three

participants included in the study, only one participant received the full eight-week music therapy process.

This research study was conducted over a short period of time and this may be seen as a limitation. While a potential shift of role identity palettes was observed in the current study, greater change may have been observed if the study had been conducted for a longer period of time.

Due to the methodology selected for this small qualitative study the findings are limited to this specific context and may not be generalisable. Detailed descriptions of the process and data were provided for potential transferability to other palliative care contexts across South Africa.

6.4 Recommendations for future research

It is recommended that further studies be conducted over a longer period of time to allow for an extended music therapy process during which identity can develop. Ideally this time period would be a minimum of six months, although due to the nature of the clientele this may not be a possibility. Another recommendation is the inclusion of a larger sample as this could generate even greater depth of research findings.

There is a gap in the literature regarding music therapy in paediatric palliative care in South Africa. This, as well as the low awareness of palliative care in South Africa, could be the impetus for future research in this field. A secondary lack of research in the literature appears regarding the exploration of identity, especially in terms of the viewpoint of the patient and how they experience palliative care. Palliative care is an important aspect of holistic care which needs to be advocated for in South Africa.

6.5 Conclusion

As there appeared to be many noticeable benefits in the participants in the short eight-week music therapy process, this research study advocates for further research to be conducted in the field of music therapy within palliative care settings in South Africa. The findings of this study support the statement by O'Callaghan et al. (2012, p. 125):

Music can offer a child a safe haven for internalising a healthy self-image alongside a patient identity. Music therapy can calm, relieve distress, promote supportive

relationships, enable self-care and inspire playful creativity, associated with “normalcy” and hope.

Palliative care is a valuable form of holistic care in the end stages of life and should be available to all children in South Africa. It is hoped that this research study will contribute to advocacy and encouragement of the growth of paediatric palliative care in South Africa, and the inclusion of music therapy in these settings.

Chapter Seven: Reference List

Abad, V. (2003). A time of turmoil: music therapy interventions for adolescents in a paediatric oncology ward. *Australian Journal of Music Therapy*, 14(2003), 20.

Adams, B. G., & Van de Vijver, F. J. (2017). Identity and acculturation: The case for Africa. *Journal of Psychology in Africa*, 27(2), 115-121.

Aigen, K. (2008). An analysis of qualitative music therapy research. *The Arts in Psychotherapy*, 35(4), 251-261.

Aldridge, D. (1995). Spirituality, Hope, and Music Therapy in Palliative Care. *The Arts in Psychotherapy*, 22 (2), 103-109.

Amir, D. (2012). "My music is me": Musical presentation as a way of forming and sharing identity in music therapy group. *Nordic Journal of Music Therapy*, 21(2), 176-193.

Ansdell, G., & Pavlicevic, M. (2001). *Beginning research in the arts therapies: a practical guide*. Jessica Kingsley Publishers.

Bottorff, J. L. (1994). Using videotaped recordings in qualitative research. *Critical issues in qualitative research methods*, 244-261.

Bradley, S. E., Frizelle, D., & Johnson, M. (2011). Patients' psychosocial experiences of attending Specialist Palliative Day Care: A systematic review. *Palliative medicine*, 25(3), 210-228.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

Bruscia, K. (1995). The process of doing qualitative research: Part I: Introduction. Wheeler, B. (ed.) *Music therapy research: Quantitative and qualitative perspectives*. Gilsum: Barcelona.

Cadrin, M. L. (2006). Music Therapy Legacy Work in Palliative Care: Creating Meaning at End of Life/Le témoignage musicothérapeutique en soins palliatifs: Créer un sens en fin de vie. *Canadian Journal of Music Therapy*, 12(1), 109-137.

Clements-Cortés, A. (2016). Development and efficacy of music therapy techniques within palliative care. *Complementary therapies in clinical practice*, 23, 125-129.

Connor, S. R., Sisimayi, C., Downing, J., King, E., Ken, P. L. A., Yates, R., & Marston, J. (2014). Assessment of the need for palliative care for children in South Africa. *Int J Palliat Nurs*, 20(3), 130-134.

Daykin, N., McClean, S., & Bunt, L. (2007). Creativity, identity and healing: participants' accounts of music therapy in cancer care. *Health*: 11(3), 349-370.

Endacott, R., & Botti, M. (2005). Clinical research 3: sample selection. *Intensive and Critical Care Nursing*, 21(1), 51-55.

Erikson, E. H. (1994). *Identity and the life cycle*. WW Norton & Company.

Finkelstein, M. A., Penner, L. A., & Brannick, M. T. (2005). Motive, role identity, and prosocial personality as predictors of volunteer activity. *Social Behavior and Personality: an international journal*, 33(4), 403-418.

Finlay, L. (2002). Negotiating the swamp: The opportunities and challenges of reflexivity in research practice. *Qualitative Research*. 2(2), 209-230.

Flick, U. (2007). Quality in qualitative research (Chpt 6). In: *Designing Qualitative Research*. London: Sage.

Forrest, L. (2001). Addressing Issues of Ethnicity and Identity in Palliative Care through Music Therapy Practice. *Voices: A World Forum for Music Therapy*, 1.

Freyer, D. R. (2004). Care of the dying adolescent: special considerations. *Pediatrics*, 113(2), 381-388.

Gibbs, G. (2007). *Analyzing qualitative data*. London: Sage.

Gray, W. N., Szulczewski, L. J., Regan, S. M., Williams, J. A., & Pai, A. L. (2014). Cultural influences in pediatric cancer from diagnosis to cure/end of life. *Journal of Pediatric Oncology Nursing*, 1043454214529022.

Hilliard, R. E. (2005). Music therapy in hospice and palliative care: a review of the empirical data. *Evidence-Based Complementary and Alternative Medicine*, 2(2), 173-178.

International Children's Palliative Care Network (2010) *Children's Palliative Care in South Africa - The Facts*. ICPCN.

Jacobs, C., & Collair, L. (2017). Adolescent identity formation in the context of vocationally oriented special needs schools. *South African Journal of Education*, 37(3), 1-10.

Kang, K., Im, J., Kim, H., Kim, S., Song, M., & Sim, S. (2009). The effect of logotherapy on the suffering, finding meaning, and spiritual wellbeing of adolescents with terminal cancer. *Journal of Current Directions in Psychological Science*, 312.

Kroger, J., Martinussen, M., & Marcia, J. E. (2010). Identity status change during adolescence and young adulthood: A meta-analysis. *Journal of adolescence*, 33(5), 683-698.

Laiho, S. (2004). The psychological functions of music in adolescence. *Nordic Journal of music therapy*, 13(1), 47-63.

Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: challenges and emerging ideas. *The Lancet*, 371(9615), 852-864.

Lin, A. C. (1998). Bridging positivist and interpretivist approaches to qualitative methods. *Policy studies journal*, 26(1), 162-180.

Linebarger, J. S., Ajayi, T. A., & Jones, B. L. (2014). Adolescents and young adults with life-threatening illness: special considerations, transitions in care, and the role of pediatric palliative care. *Pediatric Clinics of North America*, 61(4), 785-796.

Lück, P. (2014). Paediatric palliative medicine. *SAMJ: South African Medical Journal*, 104(7), 505-506.

Marcia, J. E. (1980). Identity in adolescence. *Handbook of adolescent psychology*, 9(11), 159-187.

Marks, D. F., Evans, B., Murray, M., & Estacio, E. V. (2011). *Health psychology: Theory, research and practice*. Sage.

Marston, J., Nkosi, B., & Bothma, A. (2012). Paediatric Palliative Care in South Africa. In *Pediatric Palliative Care: Global Perspectives* (pp. 27-39). Springer Netherlands.

Matthews, B. & Ross, L. (2010). *Research methods: A practical guide for the social sciences*. Harlow: Pearson Education Limited.

McFerran, K., & Sheridan, J. (2004). Exploring the value of opportunities for choice and control in music therapy within a paediatric hospice setting. *Australian Journal of Music Therapy*, 15(2004), 18.

Munro, S., & Mount, B. (1978). Music therapy in palliative care. *Canadian Medical Association Journal*, 119(9), 1029.

Nass, S. J., Beaupin, L. K., Demark-Wahnefried, W., Fasciano, K., Ganz, P. A., Hayes-Lattin, B., Hudson, M. M., Nevidjon, B., Oeffinger, K. C., Rechis, R., & Richardson, L. C. (2015). Identifying and addressing the needs of adolescents and young adults with cancer: summary of an Institute of Medicine workshop. *The oncologist*, 20(2), 186-195.

O'Callaghan, C., & Barry, P. (2010, September). Music therapists' practice-based research in cancer and palliative care: Creative methods and situated findings. In *Voices: A world forum for music therapy*, 9(3).

O'Callaghan, C., Dun, B., Baron, A., & Barry, P. (2012). Music's relevance for children with cancer: music therapists' qualitative clinical data-mining research. *Social work in health care*, 52(2-3), 125-143.

Phinney, J. S. (2000). Identity formation across cultures: The interaction of personal, societal, and historical change. *Human Development*, 43(1), 27-31.

Pillow, W. (2003). Confession, catharsis or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education*. 16(2),175-196.

Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., Chochinov, H., Handzo, G., Nelson-Becker, H., Prince-Paul, M., & Pugliese, K. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *Journal of palliative medicine*, 12(10), 885-904.

Reid, P. (2016). Music Therapy for Children and Adolescents Diagnosed with Cancer. *The Oxford Handbook of Music Therapy*, 66.

Ruud, E. (1998). *Music therapy: Improvisation, communication, and culture*. Barcelona Publishers.

Sigelman, C. K., & Rider, E. A. (2012). *Human development across the life span*. Wadsworth Cengage Learning.

Smith, J. (2005). Validity and qualitative psychology (Chpt 11). In: *Qualitative Psychology: A practical guide to research methods*. London: Sage.

Stake, R. E. (2005). Qualitative case studies. In: Denzin, K.N., Lincoln, Y.S (eds.) *The SAGE handbook of qualitative research*. 3rd ed.. Thousand Oaks: Sage.

Stein, K. D., Syrjala, K. L., & Andrykowski, M. A. (2008). Physical and psychological long-term and late effects of cancer. *Cancer*, 112(S11), 2577-2592.

Stryker, S., & Burke, P. J. (2000). The past, present, and future of an identity theory. *Social psychology quarterly*, 284-297.

Swanson, R. A., & Holton, E. F. (2005). *Research in organizations: Foundations and methods in inquiry*. Berrett-Koehler Publishers.

Su-Ming Yeo, M., & Sawyer, S. M. (2009). Psychosocial assessment for adolescents and young adults with cancer. *Cancer Forum* 33(1) 18.

Terre Blanche, M., Durrheim, K., & Painter, D. (2006). *Research in practice: Applied methods for the social sciences*. Juta and Company Ltd.

Tervo, J. (2001). Music therapy for adolescents. *Clinical Child Psychology and Psychiatry*, 6(1), 79-91.

Turnbull III, H. R. (2014). Quality of life: four under-considered intersections. *International Public Health Journal*, 6(4), 403.

Wassenaar, D. (2006). Ethical issues in social science research (Chpt 4). In: M. Terre Blanche, K. Durrheim, & D. Painter (eds.) *Research in practice*. Cape Town: University of Cape Town Press.

Wiener, L., Weaver, M. S., Bell, C. J., & Sansom-Daly, U. M. (2015). Threading the cloak: palliative care education for care providers of adolescents and young adults with cancer. *Clinical oncology in adolescents and young adults*, 5, 1.

Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2nd ed). Buckingham: Open University.

World Health Organization. Definition of palliative care. 2011. Available from <http://www.who.int/cancer/palliative/definition/en/>. Accessed September 18, 2017.

Zebrack, B., & Isaacson, S. (2012). Psychosocial care of adolescent and young adult patients with cancer and survivors. *Journal of Clinical Oncology*, 30(11), 1221-1226.

Chapter Eight: Appendices

APENDIX A

FACULTY OF HUMANITIES

MUSIC DEPARTMENT

TEL (012) 420-2316/3747

FAX (012) 420-2248

MUSIC THERAPY UNIT

TEL (012) 420-2614

FAX (012) 420-4351

www.up.ac.za/academic/music/music.html



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

PRETORIA 0002 SOUTH AFRICA

Information for head of organisation

STUDY TITLE: The function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time.

Dear Dr. Marinus

As part of my MMus (Music Therapy) degree I propose to conduct a study exploring the function that music therapy could play in the transformation of role identities for patients who have been in paediatric palliative care for an extended period of time.

I plan to conduct twelve, thirty minute individual music therapy sessions with each participant. These sessions will take place on a weekly basis during times that will be discussed with you and all involved so as not to have a negative impact on the institution's daily routine. Sessions will be video-recorded. This is standard practice in music therapy as analysis of these recordings informs the manner in which the next session is planned. Excerpts of the sessions

23

will be selected for data analysis in the research study. The video recordings will be viewed only by myself and my research supervisor. No-one else will have access to these.

All information collected will be treated as confidential and neither the name of the institution nor of the participants will be used. Pseudonyms will be used when referring to patients in the study. Please note that there are no foreseeable risks involved in the participation of this study. I will treat the participants with the utmost sensitivity and respect as to how they are feeling on any given day and will remind them that they are free to end the session or withdraw from the study at any time without consequence. Participants can potentially benefit from this experience as the therapeutic goals of the sessions will be to provide opportunities for emotional and self-expression, to create a safe space for self-exploration and to create opportunities for enjoyment in the here and now.

Participation is voluntary and, as mentioned, participants are free to withdraw at any stage during the process. Should anyone choose to withdraw during the process, all data regarding him/her will be destroyed. All data collected will be stored securely at the University of Pretoria for 15 years. No other researchers may use the data collected in this study without obtaining the consent of the participants and their parents/guardians. After completion, the dissertation will be made available through the University of Pretoria's library.

Please do not hesitate to contact me should you have any questions or concerns. I would greatly appreciate being granted the opportunity to conduct this study at your institution.

Thank you in advance.

Kirstyn Botha
Researcher/ Registered music therapy student
kirstynstar@hotmail.co.uk

APPENDIX B b

FAKULTEIT GEESTEWETENSAPPE

MUSIEK DEPARTEMENT

TEL (012) 420-2316/3747

FAX (012) 420-2248

MUSIEK TERAPIE EENHEID

TEL (012) 420-2614

FAKS (012) 420-4351

www.up.ac.za/academic/music/music.html



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

PRETORIA 0002 SOUTH AFRICA

Deelnemer Inligting vir Ouers/ Voogde

STUDIE TITEL: Die funksie van musiekterapie in die transformasie van identiteite rolle van kliënte wat in pediatriese palliatiewe sorg was vir 'n lang tydperk.

Geagte ouer(s)/ voog

As deel van my MMus (Musiekterapie) graad wil ek graag 'n *navorsing* studie doen om te verken hoe musiekterapie die manier waarop pasiënte wat in pediatriese palliatiewe sorg was vir 'n tydperk van ses maande of langer hulself kan verander.

Musiekterapie is 'n nie-indringende vorm van terapie wat u kind 'n veilige ruimte bied om hulself uit te druk, ten spyte van hul siekte. Musiek terapisessies sluit aktiwiteite soos musiek improvisasie, liedjie-skryf, sing en die speel van instrumente om net 'n paar te noem.

Musiekterapie is gevind om 'n kragtige instrument vir toegang tot die identiteit van 'n adolessent, hulle te voorsien met 'n veilige ruimte te verken wie hulle is en om in hul ontwikkeling vorentoe te

Die doel van hierdie studie is om hierdie konsep en die funksie van musiekterapie in die transformasie van rol identiteit vir adolessente kliënte wat in pediatriese palliatiewe sorg gewees het vir 'n lang tydperk van die tyd te verken. Die studie het ten doel om die waarde musiekterapie ondersoek kan vir pasiënte in hierdie kritieke stadium van hul lewens het.

U kind sal gevra word om in agt 30-minuut-lange individuele musiekterapie sessies deel te neem. Hierdie sessies sal plaasvind op 'n weeklikse basis en sal georganiseer word om in te pas by die daaglikse roetine. Die musiek terapisessies sal nie 'n negatiewe uitwerking op sy/haar daaglikse roetine hê nie. Deelnemers sal verwag word om agt sessies voltooi, en om deel te neem in hierdie sessies na die beste van hul vermoë. Die proses sal voldoen aan die individuele behoeftes van die deelnemer.

Sessies sal met 'n videokamera opgeneem word, met dien verstande dat toestemming van die deelnemers en / of hul ouers / voog. Dit is algemeen in musiekterapie as dit die terapeut om versigtig te beplan vir die volgende sessie help. Uittreksels van hierdie sessies sal gekies word vir ontleding.

Alle inligting wat ingesamel is, sal as vertroulik hanteer word en nie die naam van die instelling óf van u kind sal gebruik word nie. Skuilname sal gebruik wanneer daar verwys word na 'n deelnemer aan die studie. Neem asseblief kennis dat daar geen voorsienbare risiko's wat betrokke is in deelname aan hierdie studie en wat jou kind kan potensieel voordeel trek uit hierdie ervaring in 'n verskeidenheid van maniere. Indien deelnemers uitgawes aangaan met betrekking tot die navorsing, sal hierdie vergoed deur die navorser.

Dit sou beveel om daarop te let dat alternatiewe vir musiekterapie die deelnemer mag sessies met 'n kliniese sielkundige by te woon, maar dit sal heel anders as die terapie aangebied deur middel van musiek terapie wees.

Deelname is vrywillig en u kind is vry om enige tyd te onttrek gedurende die proses. Indien hulle verkies om te onttrek al die data wat hul betrek vernietig word.

Alle data wat ingesamel word sal gestoor word by die Universiteit van Pretoria vir 15 jaar. Na voltooiing, sal die resultate beskikbaar gestel word deur die Universiteit van Pretoria se biblioteek.

Moet asseblief nie huiwer om my te kontak, Kirstyn Botha, indien u enige vrae of kommentaar het. Ek is gekontak deur middel van telefoon of e-pos by kirstynstar@hotmail.co.uk en 071 482 2053. Ek sal u toestemming vir u kind se deelname bai waardeer.

As jy instem tot deelname jou kind se, voltooi asseblief die onderstaande toestemmingsvorm

DEELNEMER TOESTEMMINGSVORM (OUER/VOOG)

STUDIE TITEL: Die funksie van musiekterapie in die transformasie van identities rolle van kliënte wat in pediatriese palliatiewe sorg was vir 'n lang tydperk.

Ek, AMN VAN NIECKEK, ouer

ten opsigte van die bogenoemde navorsingstudie gelees en verstaan die voordele en die eise van die projek, insluitend dat my kind deelname aan agt video aangetekende musiek terapisessies. Ek is bewus daarvan dat ek enige tyd vrae met betrekking tot die studie en die proses te mag vra. Dit is aan my verduidelik dat my kind beskerm sal word en dat ek die reg het om my kind enige tyd mag onttrek sonder enige nagveolge.

Met volle erkenning van die bogenoemde, stem ek saam / stem nie saam met my kind se deelname aan hierdie studie vir die _____ (maand) van

die

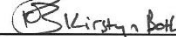
De

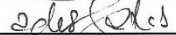
Ou

Ol

Handtekening: 

NAVORSER & STUDIELEIER HANDTEKENING:

Navorsers Name:  Handtekening:  Datum: 28/06/2017

Studieleier Naam: A. Das Santos Handtekening:  Datum: 24/02/2017

APPENDIX B b

FAKULTEIT GEESTEWETENSAPPE

MUSIEK DEPARTEMENT

TEL (012) 420-2316/3747

FAX (012) 420-2248

MUSIEK TERAPEIE EENHEID

TEL (012) 420-2614

FAKS (012) 420-4351

www.up.ac.za/academic/music/music.html



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

PRETORIA 0002 SOUTH AFRICA

Deelnemer Inligting vir Ouers/ Voogde

STUDIE TITEL: Die funksie van musiekterapie in die transformasie van identiteite rolle van kliënte wat in pediatriese palliatiewe sorg was vir 'n lang tydperk.

Geagte ouer(s)/ voog

As deel van my MMus (Musiekterapie) graad wil ek graag 'n *navorsing* studie doen om te verken hoe musiekterapie die manier waarop pasiënte wat in pediatriese palliatiewe sorg was vir 'n tydperk van ses maande of langer hulself kan verander.

Musiekterapie is 'n nie-indringende vorm van terapie wat u kind 'n veilige ruimte bied om hulself uit te druk, ten spyte van hul siekte. Musiek terapisessies sluit aktiwiteite soos musiek improvisasie, liedjie-skryf, sing en die speel van instrumente om net 'n paar te noem.

Musiekterapie is gevind om 'n kragtige instrument vir toegang tot die identiteit van 'n adolessent, hulle te voorsien met 'n veilige ruimte te verken wie hulle is en om in hul ontwikkeling vorentoe te

Die doel van hierdie studie is om hierdie konsep en die funksie van musiekterapie in die transformasie van rol identiteit vir adolessente kliënte wat in pediatriese palliatiewe sorg gewees het vir 'n lang tydperk van die tyd te verken. Die studie het ten doel om die waarde musiekterapie ondersoek kan vir pasiënte in hierdie kritieke stadium van hul lewens het.

U kind sal gevra word om in agt 30-minuut-lange individuele musiekterapie sessies deel te neem. Hierdie sessies sal plaasvind op 'n weeklikse basis en sal georganiseer word om in te pas by die daaglikse roetine. Die musiek terapisessies sal nie 'n negatiewe uitwerking op sy/haar daaglikse roetine hê nie. Deelnemers sal verwag word om agt sessies voltooi, en om deel te neem in hierdie sessies na die beste van hul vermoë. Die proses sal voldoen aan die individuele behoeftes van die deelnemer.

Sessies sal met 'n videokamera opgeneem word, met dien verstande dat toestemming van die deelnemers en / of hul ouers / voog. Dit is algemeen in musiekterapie as dit die terapeut om versigtig te beplan vir die volgende sessie help. Uittreksels van hierdie sessies sal gekies word vir ontleding.

Alle inligting wat ingesamel is, sal as vertroulik hanteer word en nie die naam van die instelling of van u kind sal gebruik word nie. Skuilname sal gebruik wanneer daar verwys word na 'n deelnemer aan die studie. Neem asseblief kennis dat daar geen voorsienbare risiko's wat betrokke is in deelname aan hierdie studie en wat jou kind kan potensieel voordeel trek uit hierdie ervaring in 'n verskeidenheid van maniere. Indien deelnemers uitgawes aangaan met betrekking tot die navorsing, sal hierdie vergoed deur die navorser.

Dit sou beveel om daarop te let dat alternatiewe vir musiekterapie die deelnemer mag sessies met 'n kliniese sielkundige by te woon, maar dit sal heel anders as die terapie aangebied deur middel van musiek terapie wees.

Deelname is vrywillig en u kind is vry om enige tyd te onttrek gedurende die proses. Indien hulle verkies om te onttrek al die data wat hul betrek vernietig word.

Alle data wat ingesamel word sal gestoor word by die Universiteit van Pretoria vir 15 jaar. Na voltooiing, sal die resultate beskikbaar gestel word deur die Universiteit van Pretoria se biblioteek.

Moet asseblief nie huiwer om my te kontak, Kirstyn Botha, indien u enige vrae of kommentaar het. Ek is gekontak deur middel van telefoon of e-pos by kirstynstar@hotmail.co.uk en 071 482 2053. Ek sal u toestemming vir u kind se deelname baie waardeer.

As jy instem tot deelname jou kind se, voltooi asseblief die onderstaande toestemmingsvorm

DEELNEMER TOESTEMMINGSVORM (OUER/VOOG)

STUDIE TITEL: Die funksie van musiekterapie in die transformasie van identiteitsrolle van kliënte wat in pediatriese palliatiewe sorg was vir 'n lang tydperk.

Ek, SIBIEMA

ten opsigte van die bogenoemde navorsingstudie gelees en verstaan die voordele en die eise van die projek, insluitend dat my kind deelname aan agt video aangetekende musiekterapie sessies. Ek is bewus daarvan dat ek enige tyd vrae met betrekking tot die studie en die proses te mag vra. Dit is aan my verduidelik dat my kind beskerm sal word en dat ek die reg het om my kind enige tyd mag onttrek sonder enige nagevolge.

Met volle erkenning van die bogenoemde, stem ek saam / stem nie saam met my kind se deelname aan hierdie studie op hierdie 26 (dag) van die Julie (maand) van die 2017 (jaar).

Deelnemer naam

Ouer/voog naam:

Ouer/voog kontak:

Handtekening: S

NAVORSER & STUDIELEIER HANDTEKENING:

Navorsers Naam: Kirstyn Botha Handtekening: [Handtekening] Datum: 26/07/2017

Studieleier Naam: A. dos Santos Handtekening: [Handtekening] Datum: 24/08/2017

APPENDIX B a

FACULTY OF HUMANITIES

MUSIC DEPARTMENT

TEL (012) 420-2316/3747

FAX (012) 420-2248

MUSIC THERAPY UNIT

TEL (012) 420-2614

FAX (012) 420-4351

www.up.ac.za/academic/music/music.html



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

PRETORIA 0002 SOUTH AFRICA

Participant Information for Parents/Guardians

STUDY TITLE: The function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time.

Dear parent(s)/guardian(s)

As part of my MMus (Music Therapy) degree I would like to conduct a research study to explore how music therapy could change the way that patients who have been in paediatric palliative care for a period of six months or longer see themselves.

Music therapy is a non-invasive form of therapy which provides clients with a safe space to express themselves despite their illness. Music therapy sessions include activities like improvisation, song-writing, singing and instrument playing to name a few.

Music therapy has been found to be a powerful tool for accessing the identity of an adolescent, providing them with a safe space to explore who they are and to move forward in their development

The aim of this study is to explore this concept and the function of music therapy in the transformation of role identity for adolescent clients who have been in paediatric palliative care for an extended period of time. The study aims to examine the value music therapy can have for patients in this critical stage of their lives.

Participants will be asked to take part in eight thirty-minute individual music therapy sessions. These sessions will take place on a weekly basis and will be organised to fit in with the daily routine. Participants will be expected to complete eight sessions, and to participate in these sessions to the best of their ability. The process will cater to the individual needs of the participant.

Sessions will be video-recorded, provided that permission is granted by the participants and/or their parents/guardian. It is common practice for sessions to be video-recorded in music therapy as it helps the therapist to carefully plan for the next session. Excerpts of the sessions will be selected for data analysis in the research study. All information collected will be treated as confidential and neither the name of the institution or of the participants will be used. Pseudonyms will be used when referring to any participant in the study.

Please note that there are no foreseeable risks involved in participation in this study and that your child can potentially benefit from this experience in a variety of ways. Should participants incur expenses related to the research, this will be reimbursed by the researcher.

It would be recommendable to note that alternate to music therapy the participant may attend sessions with a clinical psychologist, however, this would be quite different from the therapy offered through music therapy.

Participation is voluntary and your child is free to withdraw at any stage during the process. Should they choose to withdraw from the process all data will be destroyed.

All data collected will be stored securely at the University of Pretoria for 15 years. After completion, the dissertation will be made available through the University of Pretoria Library.

Please do not hesitate to contact me, Kirstyn Botha, should you have any questions or concerns. I am contactable through telephone or email at kirstynbota@hotmail.co.uk and 071 482 2053.

I would greatly appreciate your permission for your child to participate in this study.

If you consent to your child's participation, please complete the consent form below.

PARTICIPANT CONSENT FORM (PARENT/GUARDIAN)

STUDY TITLE: The function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time

I, Isabel Chafa ne
information letter regarding the abovementioned research study and I understand what this project entails, including my child's participation in eight video-recorded music therapy sessions. I am aware that I may ask questions regarding the study and process at any time. It has been explained to me that my child's confidentiality will be protected and that I have the right to withdraw my child's participation at any time without penalty.

With full acknowledgement of the above, I agree/do not agree to my child's participation in this study on this 07 (day) of this July (month) and this 2017 (year).

Participant name

Parent/guardian

Parent/guardian

Signature: [Signature]

RESEARCHER & SUPERVISOR SIGNATURE:

Researcher Name: Kirstyn Botha Signature: [Signature] Date: 07/07/2017

Supervisor Name: A. dos Santos Signature: [Signature] Date: 24/08/2017

APPENDIX C

Removed due to confidentiality

APPENDIX D

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 28 August 2018.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 22/04/2017.



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

23/02/2017

Approval Certificate New Application

Ethics Reference No.: Temp2017-00037

Title: The function of music therapy in the transformation of role identities for clients who have been in paediatric palliative care for an extended period of time [MMus - Faculty of Humanities]

Dear Kirstyn Star Botha

The **New Application** as supported by documents specified in your cover letter dated 12/02/2017 for your research received on the 15/02/2017, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 22/02/2017.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**Temp2017-00037**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:

- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Additional Conditions:

- Approval is conditional upon the Research Ethics Committee receiving permissions from Tygerberg Hospital and the REC of Stellenbosch.

We wish you the best with your research.

Yours sincerely

*** Kindly collect your original signed approval certificate from our offices, Faculty of Health Sciences, Research Ethics Committee, Tswelopele Building, Level 4-60*

Dr R Sommers; MBChB; MMed (Int); MPharMed, PhD

Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 ✉ deepeka.behari@up.ac.za / fhsethics@up.ac.za 🌐 <http://www.up.ac.za/healthethics>
✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60, Gezina, Pretoria



TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: Dr GG
Marinus
TELEPHONE:021 938 5752

Ethics Reference: Temp2017-00037

TITLE: The function of music therapy in the transformation of the role identities for clients who have been in paediatric palliative care for an extended period of time[MMus- Faculty of Humanities]

Dear Ms Botha

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.
2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

A handwritten signature in black ink, appearing to be "GG" followed by a long horizontal stroke.

**DR GG MARINUS
MANAGER: MEDICAL SERVICES**

A handwritten signature in black ink, appearing to be "DE" followed by a long horizontal stroke.

**DR D ERASMUS
CHIEF EXECUTIVE OFFICER**

Date: 3 May 2017


Administration Building, Francie van Zijl Avenue, Parow, 7500
tel: +27 21 938 4267 fax: +27 21 938 4890

Private Bag X3, Tygerberg, 7505
www.westerncape.gov.za

TYGERBERG HOSPITAL

Ethics Reference: Temp2017-00037

TITLE: The function of music therapy in the transformation of the role identities for clients who have been in paediatric palliative care for an extended period of time [MMus- Faculty of Humanities]

BY  _____
An authorized representative of Tygerberg Hospital

NAME Dr DS Erasmus

TITLE CEO

DATE 3 May 2017

R Session 1	Themes/ Roles
<p>I am not sure how that session went. I felt very disorganised and uncentred, even though I had planned the session thoroughly. There were many moments of 'unsureness' yet I felt that the session still flowed from one exercise to the next. I did not have a definite goodbye song as I did not feel it was appropriate for R but I realise now that an ending of some form is necessary. R sang his own form of goodbye as he played the guitar and I feel that this will be something that I can build on as our ending.</p> <p>As soon as R heard the first beat of the djembe he smiled, his anxiety melted away and he relaxed into the music. As he was in a wheelchair it was difficult for him to play some of the instruments but we found a way. His rhythms were short and he played tentatively. However, when he played a rhythm and I joined, together we were creating the music, he smiled and showed visible enjoyment. Yet his eyes were sad and uncertain.</p> <p>There could be many reasons for this uncertainty, it could be related to his illness but at the same time it could simply be due to the unfamiliarity of this environment and this medium of engagement.</p> <p>R showed interest in the guitar saying he wanted to learn. In the moment, I had said that our aim was to create music instead of having lessons. However, that being said in the upcoming sessions I see no reason why R cannot learn a few chords through our process which will assist him in a mastery element of his process.</p> <p>In our musical improvisation in the middle of the session R seemed confident on new instruments. His playing on the glock was simple, rhymical and played on either end showing range. However, his style of playing remained simple and on</p>	

the same level for the entirety of the improvisation. Later in the speaking of his drawing R remains on a concrete surface level and I feel this is reflected here in the improvisation. R is on the surface level when it comes to his thinking of himself and he has not explored deeper. This could be due to his age and inexperience or it could be related to his illness and perhaps it is 'easier' for him to remain at this level.

It is interesting in the drawing process that R had a wide variety of resources but he chose to use a pencil for his drawing. His picture was not coloured in and he wanted it to remain empty. His picture was grey and white, he was reluctant to speak about it in our verbal processing and his answers remained at a concrete level; "R is walking R likes school, R likes to learn, R is happy".

We began the song-writing process in this first session and R said the song must be about him, how he likes to sing, he is happy, it must be a hip-hop song about him and his family (mom and sister). When we explored this further he said "nobody must judge me, he just wants to be him." It is interesting how R removes himself from the situation and talks about himself in the third person. Perhaps this is something which happens frequently, or perhaps this is a coping mechanism for him. Another interesting aspect which came from the song his how R writes about liking to play and he wants to walk, something which is very true to his immediate circumstance of being in a wheelchair and unable to play or walk.

It is interesting that in my notes I had written that I felt unsure and unsettled when in fact when I watch the session this is not evident. This could be an experience of countertransference and perhaps is influenced by R's ADHD. Or perhaps these were simply the feelings I was left with after our final improvisation which floated between the djembe and guitar and had a scattered and disorganised quality.

- Guarded
- Lack of depth
- Lack of emotional understanding
- Concrete
- Distance
- Coping Mechanism
- Limited
- Defence

- Concrete**

<p>In the final song in which R experimented on the guitar and I accompanied on the djembe, I sang for the entire song and R did not want to sing with.</p>	
<p>R – Session 2</p>	
<p>R was confident as he entered the session today, the anxiety and hesitation seemed to not be present. This may have been related to the fact that he was no longer in a wheelchair and was now able to walk again.</p> <p>There was still some unsurity within me in the session, as well as feeling scattered, but this I feel is countertransference of the ADHD in the room. In our improvisation R becomes distracted by the other instruments. he will stay on an instrument for roughly a minute before switching and moving on to something different. This I feel could be where my feelings of scatter stemmed.</p> <p>There was meaningful connection in the goodbye song even though R and I were playing around. There seems to be a playful nature which I would like to elicit more of from R. He is a confident child yet he seems slightly serious and is always wanting to do something practical, or get on with what needs to be done. It is difficult to keep him in an improvisation due to this need, or perhaps desire, for structure. Even in the lyric analysis, an exercise to assist in lyric writing, R wanted to be told what he should highlight, instead of highlights words which he resonated with.</p> <p>As we were listening to the song R kept playing with the tubes in his hand, the tubes where the medication is inserted.</p> <p>We then discussed what our first song was going to be about. R said “care”, saying we must care for people. When looking at the lyrics R chose the word ‘dream’ saying his dream is to one day be a singing superstar. R is fascinated and obsessed with hip-hop, and as we spoke about his dream he said that</p>	<p>“The Red Devil”</p> <ul style="list-style-type: none"> -Confident -Rule Breaker - “Naughty” <p>Mastery</p> <ul style="list-style-type: none"> -Experimenting -Learning -Determined -Aspiration -Investment -Agency -Playful (Child)

he was going to rap and sing and that's how he would be a superstar.

As we were discussing the song lyrics R said that we couldn't say "I" and instead he wanted to put in a fake name. I suggested R which he liked but then as I wrote it he said it must be the "Red devil". It is interesting that this was the particular fake name he wanted. Perhaps he sees himself as evil, or bad, which is in contrast to the person o have seen in the two sessions we have had. This is his particular way of identifying his self at the moment.

It is interesting to note that he used the fake name but then the rest of the verse is in first person. R is capable of speaking in third person, which was evident in our first session, but now he chose to speak in first person, despite using the fake name.

All the lyrics including the title were written by R.

The Dangerous Rappers

We must care for one another

Love one another

We must keep on dreaming

Your dreams will one day come true

Red devil wants to be himself

Nobody must judge me

I wanna judge myself

If you know what I mean

You must love your family

You must love them more than anything in this world

<p><i>You must love your sister more</i></p> <p><i>Cause she is your blood</i></p> <p><i>If you know what I mean</i></p> <p><i>Yeah, Yeah</i></p> <p><i>If you know what I mean</i></p> <p><i>Yeah, Yeah</i></p> <p>As we were writing the song R kept asking for specific formats of the song, how many words it should be, how many songs is this. There is something about wanting to do what he needs to do and fulfilling what is expected of him. This mindset could be perhaps due to the fact that his participation is for research and he understands that certain things may be expected to happen. Or this could be a much deeper engrained behaviour pattern due to his illness and possibly needing to meet certain medical requirements in order for things to happen, like being able to go home for example.</p> <p>The remainder of the session involved R instructing which parts of the song were to be sung or rapped, which instruments were going to be played and how it would sound. He was quite instructive and direct about what he wanted, and also what he did not want. R is not afraid to say no.</p> <p>To close off the session R played guitar and I djembe. I sang goodbye. R was playful and animated in his playing and body language. He sang goodbye to me and I to him. We sang in a mocking style, playing and overexaggerating as we sang goodbye to one another.</p>	<p>Patient</p> <ul style="list-style-type: none"> -Rules -Requirements -Structure
<p>R – Session 3</p>	
<p>R was now at school and discharged from hospital. He attends a special needs school in a nearby area. His opening improvisation was confident, loud and controlled. His rhythm</p>	

was lively and this was in contrast to his first djembe improvisation.

R's curiosity came in and he experimented on the new instruments. I then incorporated this into the improv and we played on different instruments, with a basic beat going throughout. This I felt managed R's ADHD and easy distractibility. None of the improvisations lasted longer than a minute.

When we spoke about his holiday R said that he did a lot of chores. I asked him for three words to describe him and he said "I like to laugh, helpful and I like to do things (working)".

R asked about his song and so we worked on the music for the song. R tried out the different instruments switching from cymbal to glock, percussion and drums. Once the song had been rapped R went into an improv on glock which I followed but this only lasted a minute before he moved on to the next instrument. This caused me to become uncentred. I felt as if we were flitting between instruments and there was a lack of continuity in our sessions. It felt jarred and jagged. This was due to me simply wanting to accommodate R wherever he wanted the session to go. As this is only the third session I felt that this was appropriate, although that being said I should have provided a more musical structure in which R could experiment.

R wanted to put his song into the framework of the song we had listened to in our previous session. This could be related to his need of structure, and doing what is required. Perhaps by putting his song into an existing songs structure he was conforming to an 'actual' song's standards.

This was tricky though and instead we vocally improvised, taking turns on a chord sequence, to find our melody. R was willing to use his voice, something which he was more freely expressive with compared to our first session.

Worker

-Responsibilities

-Chores

-Helper

We sang together and naturally found a melody we liked. We repeated it and then put the words to it. This formed the chorus of our song and the verses were rapped by R.

The song had been the longest musical element in our process so far. In the music R was focused on singing and playing. Perhaps the length of his involvement was a representation of his investment in his song. R played the glock as we sang through the song, together we created coherent music which flowed. There was meaningful connection in this improvisation which I feel was the cause for the flow of the song.

The session ended with R on guitar. He learned how to play Em and we improvised on this chord, which fit with our goodbye. He experimented with the chord and showed enjoyment in being able to play a 'real' chord on the guitar.

R used his voice more freely in this session, particularly the improv and the goodbye. This shows he is increasingly comfortable in the space as well as in our relationship to use his voice. It could also be related to his increased confidence.

R – Session 4

I had brought the piano along for this session which R was immediately fascinated by. This ended up being a distraction point rather than a helpful tool. I felt that I, once again, followed R wherever he went, instead of providing him with structure.

It is easy to get swept up in the scattered thinking but at the same time it is disorientating. I felt that the session was demekaar and jumping from one thing to the next. The fact that the keyboard had multiple buttons did not assist in the situation. In the following session, I will be firmer with R, saying we had to pick one sound only and at the end of the session perhaps allow him to choose a different sound.

In the following session, I will bring fewer instruments. this will assist in keeping R's focus on one thing at a time. It will help to make the session easier to manage.

The piano improvisation was multifaceted. There were moments where R and I engaged in a musical dialogue, then moments where R would completely dominate the piano and other moments where it was quiet.

In some sections R played a melody while I accompanied him, in these moments there was connection and relationship but they would last for no longer than a minute. While the time actor may be due to R's ADHD it could also be attributed to the relationship felt in this improvisation and as a defence to stop, therefore withdrawing from the connection.

There were moments in the improvisation where the music was harmonic but then other moments where it was atonal and chaotic. R experimented with different sounds on the keyboard, looking for a new sound for our new song. This song had to have the chorus of a Chris Brown song and then we wrote the lyrics for the verses. Once again linking to R's need for the structure, or to do things according to a certain mandate. However, now he is allowing himself to experiment within this structure by adding in his own words for the verses.

R chose the theme for the song as Love. Love for his mom, dad, sister, grandma, family and girlfriend. It is interesting that he adds his dad to this list, as he had mentioned in the first session that there was no foster dad in his life, only his foster mom.

While our session today seemed disorganised I feel that it needed to be that way in order for R to experiment and this was the way in which he experimented, in a way that was true to him and his personality.

- Love
- Caring
- Kind
- Sincere
- Loving
- Careful
- Extended Range
- Deeper Understanding
- Emotional Intelligence
- Increased Awareness

R – Session 5

I felt calmer and more relaxed in this session today. I centred myself before the session began and I feel that this in combination with R feeling comfortable helped us to find a middle ground. Perhaps my being centred resulted in R being centred.

I gave the session more direction, had fewer instruments present and was more directive in my approach. I felt that this is what R needed from the session and it proved to be correct. R was more focused, calm and together as we worked through the session.

R was more assertive in our opening improvisation but that being said he did not play at a high volume for the entirety but instead interchanged with softer playing, this was a first. This shows the expansion of R's range and his ability to not only play loud and with confidence but to play with confidence softer.

R wanted to work at the piano but when we got there I gave rules for playing at the piano which included staying with one sound per section. This assisted me in keeping R focused on the song we were writing. A song that R suggested we write.

R may have been influenced to write songs throughout the process from the first session in which I had suggested that we were going to write a song at the beginning and the end. From then all R had asked to do was write songs. This I feel is due to the relationship we have and he wanting to do 'well' as the research participant. I addressed this by introducing other modes and techniques in the session but R was intent that he wanted to write songs. Perhaps my interpretation is incorrect and R found joy and release in writing songs, here was a medium for him to express what he was feeling inside and he enjoyed doing this.

We spoke about the theme to our song and I played the chord sequence. We discussed the different people in his life that he loves and he became shy when talking about the love he

has for his girlfriend. R gave the intention that the song would be something we could say to the people he loves. He wrote the following words:

I love you more than anything in this world

I will never let you down

I love you, I love the way that you smile

I think that you are the most beautiful girl

These two verses became the verses of the song while the chorus came from a Chris Brown song, Welcome to my Life.

The song then went as follows,

I love you

More than any-thing in this world

I will ne-ver

Let you down

Have you been there

Have you seen it all?

Have you done this once before

Did they tell you

That you'll love this life

Now you're lying on the floor

And they know what doesn't kill you

Makes you want it more

This is your life, your life

This is your life

I love you,

I love the way that you smile

I think that you

Are the most beautiful girl

There was cohesion between R and I as we sang the song and arranged the lyrics to fit with the melody. Writing the lyrics for his family R found easy but to write for his girlfriend he struggled. He asked me to write it but instead I asked him prompting questions which lead us to the second verse's words.

When R struggled to write the words, I did wonder if he indeed had a girlfriend but through our discussion I realised he did and in fact he was simply shy. He is a 13-year-old boy and it isn't surprising that he would be shy to talk about his girlfriend, who is most likely his first girlfriend.

R showed agency as we sang the song, adding in his voice in silent sections and continuing the song after the words had ended. I continued to play piano, accompanying his voice and his investment grew. He seemed more invested in the chorus (precomposed) than in his own verses but this could be due to the fact that these verses are quite personal and the first time we have truly began to dig deeper.

This stage for R was a crucial development and showed his capacity to begin to truly and fully express himself, as well as to explore his emotions, even if he needing prompting here and there.

When the song was finished R asked to play piano and so we improvised. The music began soft and legato but then it grew, it became staccato, forte and rhythmical. R then changed the sound and the style changed to long single notes intertwined

with a few faster notes. R changed the sound again, and I explained it would be the last one for us to end on, R chose the precomposed backing track for the keyboard and played along. He was invested in the music, moving his body to the beat and actively playing along.

R asked for a soft sound and so I placed a pad effect on. We played legato notes, R single notes and I on chords. I began singing goodbye to him and he stopped me saying that “it cannot go on like that!” He chose a staccato pad and we played a lively improv. R changed the sound again to drums and I rapped goodbye to him. There was a need for me to physically end the session and I did this through discretely unplugging the keyboard at a strategic musical moment. R seemed upset but he knew it was time to go. R’s awareness of not only himself but of his surroundings is evidently growing.

R – Session 6

All R wants to do is write songs and I suspect this has been a freedom of expression for him which he is enjoying. I offered other modalities, again, in the session but he simply wants to write more songs. I tried to encourage him to draw with a specific intent, or listen with intent but he wanted to write another song.

R’s hesitated at the beginning of the session, saying he did not know what he wanted to play. He then began playing softly, without confidence and gently on the side of the djembe. I followed his playing, encouraging him musically. This is an interesting reaction from R who has been confident since our second session. This could be as R was feeling differently in our session or because we had been speaking about this being our third last session. This discussion may have had an emotional impact on R, knowing that we will have to end soon.

Sincere

The improvisation began small and soft but then grew and became louder. It lasted a minute before R ended it, asking if I had written the song down. His interest has been primarily on the songs throughout the process. These songs, I feel, are a physical representation to him of his feelings. Particularly if I think about our first session and how he was unable to access these feelings, and spoke concretely, that now song writing has become an access tool for him.

We sang through our song from the previous week and R chose to play the glock. I left the song in the key of E major and let R play what he wanted on the glock, intentional mismatching. He played with for a verse and a chorus, his music was slightly atonal, he then asked me to stop so he could change instruments. I had done this mismatching on purpose to gauge R's response and his response was to change instruments so that he could harmonically fit in with the song, showing his greater awareness of the music, and unintentionally the person next to him, not only focused on himself but the greater picture.

He wanted to "play something more interesting" and chose the two-tone block. We improvised as he explored the instrument and went into the song which we sang through a few times. R showed agency in the music, leading the direction of the song, even verbally at one point. He wanted to play it through with him playing different instruments, djembe, shaker, hand cymbals.

R titled the song *Loves of My Life*.

He then wanted to begin another song using the melody off 'Despacito'. R said that we were now going to write a song about town, his place. He said his place was bad, it wasn't good, that's how we do it in my town. When I asked prompting questions, he said he did not want to talk about it. He said that he enjoyed the other song and it was beautiful, this other one was dark and we mustn't write it. I explained that not all

music was beautiful and good, some music was dark and bad. I did not like using the words good and bad but it was R's words and I knew that in order to relate to him and for him to understand I needed to use his language.

He then said he didn't want to write about 'my place' anymore. I rattled off what we had written about, family and love, and he asked for me to give him something. I suggested his name and he said yes, he likes it. I asked me to tell me about himself. He came up with the following words; **I'm handsome, I care, I love, sometimes I'm moody.**

I had to ask prompting questions but he came out **with 'I like to work and help out, I like to play.'**

He struggled to think of more information and so I asked him about the place we met, the hospital. He said that he only goes there **"when I get sore."** I asked him if that happened easily and he said yes. I asked him if that means he had to be careful and he said yes. He then said we could put that in the song and so one of the lyrics became **I'm careful.**

We spoke about the logistics of the song for a few moments. I feel that R redirected the conversation this way in order to avoid talking about his illness. Him opening up about it was a big step for him and one which needed to have a nonconfrontational release, I feel, and this was done through talking about things, once again, at a concrete level. We then listened to Despacito in order to get an idea for the structure of the song.

R asked if the last part of Despacito could be included in the song. He asked if I could put drawings on the songs. I had said I would give him the songs at the end of our process together as a gift as he had been asking to take my speaker at the end of our time together.

I asked if we could sing goodbye and he said "I don't want to sing goodbye. I'm sad now, you're leaving and going to

Joburg and you don't want to give me nothing." I assured him I would see him once more before my trip and he would receive the songs at the end. He said "I'm going to climb in your bag and you're going to take me with you." This shows me that there truly is a relationship between us and it is in this, the trust that comes with this, that R is able to open up to me. Through this trust I will be able to assist R in exploring his sense of self, which has been evident so far.

This discussion lead into a closing improvisation in which R played the drums on the keyboard and I sang along with played guitar. **There was synchrony and connection between us and the music flowed. I feel this was possible through the moment we had had in the discussion. It was short, as were most of our improvisations, but I feel that it was authentic.**

R – Session 7

R's energy was back in this session and he had a more positive outlook on our ending process. This was an insightful session and R was interested in the other participants of the study. I did not give much information and simply said they were from the same hospital as him. He did ask if he knew any of them or if they were "a bleeder like me?" I diverted the conversation, even though R was persistent.

I felt that this was a powerful session. R opened up about his illness and wrote a verse in his final song about it. From the moment, we began the first improv he was asking about his song. **He is invested in writing these songs and I feel that it is due to him being able to express his emotions, which he has been unable to do in the past, or even in the beginning of our process.**

To lead into the song-writing process, after our opening drum improv, **we sang through the second song we had written. This assisted in breaking the defence mechanisms which may have been up from outside the therapy space. There was rapport and connection as we sang through the song,**

R's voice broke at one point he was singing so hard. We ended together and there was silence, words weren't needed.

I asked him what he thought about now when we sang the song. "A lot of people. It feels so lekker. I like it."

He expressed desire to continue with our other song. When I asked if it was finished, which in the previous session he said it was, he now said that it wasn't. He wrote the following two lines; I don't like people whose boring, I don't like people whose moody. He stopped and struggled. I asked them if there was anything about himself he wish he could change. He said "I wish I could change my illness." I asked one question, "why do you wish you could change it?" He responded that he couldn't do what others could and he didn't like his illness.

The song was finished. The first verse spoke of the 'nice' things about R and the second was the things he didn't like. As we negotiated the melody with the lyrics R said that we must take out the lyric *I'm careful*, because it didn't fit with the first verse but it mustn't be in the second verse.

R only wanted the two verses and then the chorus of Despacito. I brought the words to learn with him but after attempting to sing it once R decided to leave it out altogether, leaving us with two verses.

We stayed with the chord progression of Despacito. The first verse fit with the melody of Despacito. We then improvised in between verses and from this improv stemmed the melody for the second verse. R sang and played djembe for the first verse but he did not sing for the second verse, the verse about changing his illness. This is not unexpected as it is a sensitive subject and one which I'm sure was difficult for R to express verbally. I also suspect that it is easier for him to rather let someone else sing it. He did not have any qualms

with me singing it and even sat back at one point and said
"sing it to me now."

When the music finished R asked if he could come with me again. When prompted why he said that it was boring there. I speculate that due to our relationship, and my being able to support all aspects of who R is as a person, it will be a difficult goodbye due to the deep connection and relationship that we have developed. This is very different from the beginning of our process together in which all R's contributions were on a concrete level, and now a deep level of connection and emotional expression.

As we spoke R began singing the chorus for *I don't like it*. He then wanted this to be in our song, we now had our chorus. R changed the words so that it fit with his song, and titled it R (his name).

R

I'm handsome, I care

I love, Sometimes I'm moody, yeah

I like to work and help out

I like to play

I don't like people who are boring

I don't like people whose moody

I wish I could change my illness

I don't like it

I want to do what others can do

But I can't

I don't like it

But I want to want to change it

Oh yeah,

And be good and strong

To end the session R played the Em chord he knew which was the opening chord for Despacito, which he acknowledged. We then hummed through the song and improvised to end the session.

There was an element of mastery in this improvisation as R played the chord and I improvised on piano, using chords related to E minor so that his one chord could be harmonised in many different ways. This led us into singing goodbye to one another.

As the session ended R took the speaker and then my pen when I said no. when I asked why he wanted something of mine he said *“because I’ll miss you.”*

R – Session 8

This was a very interesting goodbye and final session. I felt like R rushed the ending and when we walked back to class he ran, possibly to avoid saying goodbye, or spending time on saying goodbye. This was perhaps due to him not liking endings, especially after the past two sessions in which he had shown that there was an authentic relationship between us.

I had brought the drawing from our first session to this session which I felt was a good idea as it helped to round off the process and to reflect on how far he has come. It provided me with a lot of insight into how he viewed himself then to how he views himself now.

R began the drumming quite small, more preoccupied with what I had brought for him, and then it grew, becoming more rhythmical and introducing pauses. As soon as it was done I was asked what I had brought for him. I showed him the songs I had printed and put on coloured board. I handed the

rest of the session over to him letting him know we could decorate his songs together with the art supplies I had brought.

He said he wanted to sing his song, and we sang them all through. When we sang through his most recent song R did not sing with. I allowed myself to improvise and to follow the mood given from R. The song began as we had rehearsed but as we got to the second verse the energy and intensity increased. I increased the volume but kept the tempo steady. I sang the second verse and improvised as I did so. R played the drums on the keyboard and at one point put his head down, moving it in time with my rhythm. In this moment, I felt the connection and intensity grow, someone could cut the air with a knife. As I sang the words *I wish I could change my illness* R sang with me. This was a meaningful moment for him, his feelings and desires were being brought to life through music. I felt that the music we were creating was a true representation of what he wanted.

We then decided to sing the songs one after the other. Starting with the first song written, second was the last song and we finished with his favourite song which was the second song we had written together. R played the djembe, sang and rapped, while I played guitar and sang.

When we sang through and came to the last song we had written it was filled with emotion, even though R hardly sang. It was evident in the music, the way it built and the intensity of it, there was a lot of emotion. R did not make as much eye contact in this song but instead took the beater and hit the djembe as loud as he could with a driving pulse. It was necessary for us to move onto the second song last as there was too much raw emotion in the song we had just sung, we needed something fun and uplifting in order to close off the emotions. The order R put the songs in is quite significant.

The energy from the middle song transferred to the final song, R sang all the words to this song, as it was his favourite. We ended on a strong and intense note, and we ended at the same time.

We then moved on to decorating the songs together. R told me exactly how to decorate one of the pictures. I used this as an opportunity to chat and reflect without the confrontational style of face to face discussion. It was easier for R to open up if we were distracted by the decorating.

As we drew we discussed his life, how he has learnt that he must care for himself and be careful, because of his illness. he said that he doesn't care for himself but through this he has learnt that he has, perhaps a preservation of life, finding hope in life despite the illness. he said his mom does care for him, and so does his girlfriend.

It is interesting that the first song he decorated with his friends' initials. This is also the song which he did not seem to connect with as much as the others. Perhaps this first song, written at the beginning of our process is more a representation of his friends and his friend group's identity, rather than a representation of himself. Not to say that this does not represent a part of his self but rather it is not his whole self. I feel that the other two songs are more a representation of his true self, or perhaps shows he has changed his perception of self.

The final song we had written, which I feel is the song with the most emotion in it, especially when we play it, R asked for hearts to be placed around it. I find this appropriately fitting for this emotional song.

I asked him what he was going to do with the pages and he said he was going to keep it as his memories. I asked if they were happy, sad or angry memories and he said happy. We discussed the songs. When I asked if any were difficult to

write he said the last one was difficult to write but the second one was his favourite.

When we were finished, to end off the session, I asked R if we could look at the picture he drew of himself in the first session. I asked him if this boy was different to the boy he saw himself as now. He responded yes and I asked him how. He said "a lot of things. He is very, like, he don't want to go to hospital. And he is careful." R thanked me and told me to come back again. I walked him to his class and we said goodbye. It felt like a rushed goodbye but I got the sense that R did not want to spend time on the goodbye as it may have been difficult for him, it was certainly difficult for me.

T – Session 1

This session flowed and there was a lot of connection as we improvised. T has a lot of spunk and energy despite being so sick. He took initiative with the consent form and read it himself, despite me offering to read it for him. He took his time but wanted to read it out loud himself.

T showed great investment in the process. In filling out the consent form he had to design his own signature, which he smiled to himself while doing, he was interested in all the instruments I had brought, which was evident in his body language. He lay in his bed for the session as he was too weak to move but he sat upright, peering down the side of the bed to see what I was playing.

T began on the snare drum, he sat in his bed and played. I played djembe and T began playing a rapid, repetitive beat. He experimented with different ways of playing the snare and his rapid beat was replaced by a slower, rhythmical beat. I added my voice. T looked at me and nodded, investing himself in his playing.

When asked to sing T's playing became disorganised and he sang one motif. He then said he couldn't do both and

Energy
Inquisitive
Child
Playful
Experimenting
Enjoyment

continued to play. When the improvisation ended T was curious as to how the other instrument sounded and began experimenting. As soon as he saw the guitar he wanted to play it. He enjoyed playing the guitar and this will be something we can learn in our sessions, perhaps even learn a song.

T strummed the guitar, bending his head down to the hole. I played snare to accompany him and then added my voice, singing a four-note motif. He looked at me every few moments and smiled or nodded his head. There was a sense that we were co-creating music together and a connection formed, the beginning of a relationship. T seemed to be enjoying the music he was creating.

The improv was interrupted by the doctor for T to receive his chemo. It was injected into the hand he was strumming with and he winced and whimpered in pain. I had invited him to play softly, as I had seen the pain he was in, but he immediately began strumming the guitar again and looked at me as if he was ready to carry on. This surprised me, that this boy who was in pain still wanted to carry on with the music. The medicine was simply an aspect of his life but he wanted to play and therefore he was going to play.

T continued to strum, repetitively, and I accompanied on snare. I would match him but then move away from the perseverative beat and add in a rhythm, to vary the music. T would occasionally look at me from the corner of his eye and smile. He enjoyed the music, even though his playing was very repetitive and even perseverative. I felt connection with T in this improv, even if his playing was repetitive. He would look at me, make eye contact and smile; he was playing the best he could and my variation added another layer to the music. T began singing with me and he managed to sing and play at the same time. He showed enjoyment in the music, a welcome distraction from the hospital environment.

Determined

Resilient

T introduced an accented beat, which he accented more through his body movement, and I emphasised this by exaggerating my playing and body movement. We played a few repetitions and then ended together, T looked at me and laughed.

I offered the choice to T to draw and he said yes. However, as I was prepping this he began to play guitar again, I sang as I got the supplies ready. I took the opportunity, as this felt spontaneous and true to him, whereas drawing felt less natural and more forced, to move back to the instruments and play with him. T began strumming a more controlled pattern and singing a song he knew. I played the djembe with him and he stopped playing and tried to teach me the words.

There was something in the way he stopped to teach me the words that was special and profound. I listened and caught on, although I could not hear all the words and T began playing again. I sang with him and he looked at me and smiled when I got the words right. He finished the song and wanted to try another one. T played guitar for our final song, the goodbye song. He showed engagement and involvement with the guitar and the entire process, ending the session by saying "this was my day."

F – Session 1

F was very weak when I saw him and his session only lasted 10 minutes before he called for his mom, asking to stop.

As I was setting up the instruments in his room F played the cymbal with a beater in a specific rhythm. I sang with the rhythm. He smiled and looked at me. I showed him the other instruments but he was drawn to the cymbal and the snare drum. His playing was very rhythmical. The cymbal and the snare were the two instruments which required him to use beaters only and he could play lying down in his bed.

Before we started our improvisation, F counted us in by hitting the beaters, as drummers do in the movies. It took us a few moments to find our groove but once we found it there was continuity in the music and a connection began to form. F looked at me, making eye contact, and smiled as he played. This improvisation felt connected and as if we were listening to each other and creating this lively, energetic music, together.

It is interesting that F chose the biggest and loudest instruments in the room, despite his physical appearance being small and weak. The instruments, perhaps, are a representation of his true self. His joy was evident as he played them and perhaps this is the space where he can be who he truly feels he is.

After two minutes F stopped, a grimace on his face. He struggled to breath and took deep breaths. I played softly, humming for a moment, and then asked him if he could sing me a song. F laughed. He looked as if he was in pain and his breathing became short and shallow. I asked him if he was okay and he said he wasn't. He had some juice and seemed to be okay.

I decided to change the pace of the session and we had a discussion about different types of music. F likes gospel music but also Kwaito and Mandoza. F began coughing and I checked in to see if he was okay to carry on. He grimaced but picked up the egg shakers. Perhaps the egg shakers represent 'sick' F whereas the cymbal and snare represent 'true' F?

I constantly checked in with him as F was weak and I did not want him to overexert himself. F began to play the shakers rhythmically and I played on one string n the guitar. This was only for mere seconds before F stopped again, this time asking for his mom, saying he was struggling to breathe. While I went to call his mom, F experimented with the

different types of smaller instruments but this was brief and by the time we returned he was in pain calling for his mom.

Interesting that the desire to play is sitting within him but his physical body simply won't allow him to continue.

F – Session 2

This was an interesting and sombre session. F, after weeks of not feeling well enough to have a session, agreed to a session as long as it only involved listening. He did not want to play any instrument.

We spoke about music and what artists he likes. F was reluctant to give any names but when names were suggested he nodded his head. He is quite closed off and I speculate whether his is his way of protecting himself. He has been very ill and most likely close to the end of his time. Perhaps this is his form of protecting himself, and not letting anyone in because there isn't any time, or he may not see the point in doing so.

We listened to a relaxing popular song and I guided F through a relaxation, using the theme of *my happy place*. F did not close his eyes and instead stared straight ahead at the wall.

I asked F if he had a happy place and he said no. this is understandable for a child who has suffered with this illness for so long. I asked him if there was a place he knew he could go to if he wanted to relax and he said there was. He did imagine this place even though he seemed to struggle with at first however, he did not want to tell me about it when I prompted him.

Throughout the session I got the sense that F was incredibly sad. It seemed as if he had come to the realisation that the end was near for him and along with this sadness his eyes showed fear, as well as tiredness. It is not surprising that he did not want to share his relaxed place with me as it seemed

that it was personal for him, again a defence mechanism having his guard up. It is interesting to note, though, that his breathing became deeper and less shallow as the song continued, perhaps a resemblance of F relaxing.

However, when the music finished F said he felt 'painful' and his chest hurt. His tiredness I speculate stems from his body being tired having to constantly fight this illness. It hurt F to speak and he reverted to nods and shakes for the majority of the session.

I felt completely helpless and deeply sad after this session. This child was shutting down before me and I did not have the resources to help him. Any participation seemed to cause him pain and when he did participate it was from a guarded place where I was not allowed to enter. This is completely understandable, I only wish there was some way I could have helped him, more than I did.

When F coughed and expressed pain I asked him if he wanted to stop and he said the word 'stop'. I assured him this was okay and we could always stop whenever he was not feeling well. Reiterating that even when I arrive for the following session he could say no to having a session, as he had done on previous occasions.

When our session was finished he said that I could bring the drum and cymbal for him to play in the following session. I feel that for the next session I need to be prepared with a few songs that we could play together.

The Dangerous Rappers

We must care for one another
Love one another
We must keep on dreaming
Your dreams will one day come true

Red devil wants to be himself
Nobody must judge me
I wanna judge myself
If you know what I mean

We must care for one another
Love one another
We must keep on dreaming
Your dreams will one day come true

You must love your family
You must love them more than anything in this world
You must love your sister more
Cause she is your blood
If you know what I mean
Yeah, Yeah
If you know what I mean
Yeah, Yeah

LOVE

WELCOME TO MY LIFE

VERSE 1

G#m E
I love you more than anything in this world
G#m D#m
I will ne-ver let you down

CHORUS

G#m
Have you been there?
E
Have you seen it all?
C#m D#m
Have you done this once before?
G#m E
Did they tell you, you'll love this life
C#m D#m
Now you're lying on the floor
G#m E C#m D#m
And they know, what doesn't kill you makes you want it more
G#m
And this is your life
E C#m D#m
Your life, your life

VERSE 2

G#m E
I love you
C#m D#m
I love the way that you smile
G#m E
I think that you
C#m D#m
Are the most beautiful girl

LOVE

R

I'm handsome, I care
I love, Sometimes I'm moody, yeah
I like to work and help out
I like to play

I don't like people who are boring
I don't like people whose moody

I wish I could change my illness
I don't like it

I want to do what others can do
But I can't

I don't like it
But I want to want to change it
Oh yeah,
And be good and strong

APPENDIX F

Thick Descriptions

R-1

R and I are sitting, fairly close, next to each other at a desk. R is in a wheelchair while I sit in a chair. R finishes off his drawing, a self-portrait, with a pencil. R is closed off and does not make eye contact.

“Can you tell me anything about him?” I ask R in a gentle speaking voice, breaking the silence in the room. R looks at me questioningly then his drawing and back at me. He smiles coyly, unsure of what I am wanting from him. I then ask him further “Do you want to talk about him?” in a questioning but relaxed tone, not wanting to pry if he was not ready to share.

“Um...about him?” R responds with, seemingly still unsure, although he shyly smiles. “Ja, and about you. About the you that you drew” I continue to say. R sighs despairingly and looks at me, he then smiles and shakes his head, looking down at the desk. He is avoidant, defensive and closed off. I sense this and change line of questioning, staying more concrete and giving the questions more direction, instead of being open. “I see he is walking.” I say to R.

R nods his head, matter of factly and in agreement. His face is blank, showing the expression of ‘so what’. There is palpable silence in the room. I continue with my concrete questioning, gauging that this is the best approach, “Is he going somewhere?” R immediately responds by nodding enthusiastically and in affirmation. “Where is he going?” I ask and he responds with “To school.”

“Do you go to school while you’re here?” I ask and R immediately looks down at the table, despondent and slowly shakes his head. I steer the conversation in a positive direction and ask “Do you like going to school?” and R nods, resting his head on his arm, seemingly uninterested, guarded and a hint of boredom. “For the learning or for your friends?” I ask and R responds promptly with “To learn.”

I ask him “What’s your favourite subject?”, keeping the conversation concrete as I can sense the defences are present. And R responds with “Math” in a casual manner, not making eye contact and fidgeting with the drawing. “Maths? Mine too.” I say this, finding a commonality

between us. R nods and continues to fidget with the page. He sits back and looks at me expectantly. There is silence once more in the room.

Sensing that this is not a topic he wants to discuss further I change the direction of the session “So, we are going to be writing a song.” R gives a slight nod and seems interested as I pick up a piece of paper and a pen. He watches my movements, not wanting to show too much interest but just enough for it to be noticed by me. “I would like us to write down some words, about you, now, and the you that you drew” my voice now carrying a bit of weight and intention, expecting more of a response from R.

R looks down at the page and then at me and then back down at the page, unsure and slightly confused. I elaborate and explain further by saying “So, what can you tell me that stands out about you, and the you on the page?”

R understands and immediately responds, in a gentle speaking voice, “I like to sing.” I affirm his contribution by repeating it back to him “You like to sing, and what else?” R fidgets with the pencils and give a coy, shy smile. “He like to sing” he says and points to his drawing. R does not make eye contact, only looking at the picture and then to the pencils he is fidgeting with. “And to walk?” I ask prompting him to speak about himself by speaking about the picture. R casually nods and continues to fidget with the pencils.

R continues by saying “and I like to play”, his facial expression is neutral and he is casual in his mannerisms. “He likes to play and walk” I say as I am writing this down, “And go to school?” R gives a gentle nod in affirmation and fidgets, looking down at his drawing, not making eye contact. Feeling he is ready to slightly open up emotionally I ask, “What type of type of person are you? Like the R on the page. Are you a happy person, a sad person, an angry person...?” R immediately responds with a smile and says “Happy person!” R then accidentally knocks a pencil that it rolls off the table. He watches it in astonishment as one drops and then two more. He smiles and finds it funny. I count “1, 2, 3” as they fall on the floor. R looks at me with a joyful smile.

“And the music that I played? Did you like that music?” I ask gauging his musical interests. “I like that music!” R says with conviction and a confident head nod. “Chris Brown. So, when we write our song I think it should definitely be a hip hop song?” I ask him and he responds with “Yep!” casually nodding his head, R then looks at me, continuing to fidget with the pencils. I keep the topic of conversation on the music and our intention for the song we are going to be writing, asking “Shall we rap in it?” R likes this idea and smiles coyly, he then looks at me then down to the pencil he is playing with. He has become shy.

“Like why, what?” he shyly asks while smiling a nervous smile. “We can make it up together” I tell him encouragingly, trying to ease the obvious nervousness. R then changes the direction/intention of the exercise and says “We must sing a song and we must learn it”, wanting to learn a precomposed song. But I respond by saying “We are going to make the song together. We are going to write all the words and put the music to it. You are going to write the words. And then I will write the music for it.” R looks down, uncertain about this task, but he slowly nods as he thinks about what is being asked of him. R avoids the task again by saying “I must sing the words. You write them.” But when I said “You’re going to write them as well.” R complained and said “Nooo” He said it in a playful manner but his voice is not convincing as a proper rejection of the idea.

I encouragingly say to him “We will write it together.” But R diverts the task, smiling nervously and saying “I want to sing, I don’t want to write it.” I prompt him no this and ask “Why not?” and he responds with “I don’t like to write.” As he says this he does not make eye contact, he seems uneasy in this task being asked of him. “You don’t like to write. Well what if I write it down and you can tell me what to write?” I compromise with him. R nods wearily but accepting the task, the smile disappearing from his face. He looks down at his page and begins to play with the hair on his head, which is short.

“So, what is our song going to be about? We have these things that you like to do; to sing, to play, to walk, school, happy and you like hip hop. What else can it be about?” He responds confidently, yet with an upper inflection in his voice “About me.” I affirm his contribution “About you, ja.” R then whispers “And my family.” R watches me intently as I write down his family. I prompt him by asking “Who is in your family?” and R responds with a bashful smile saying “A lot of people”. I prompt him further “A lot of people? Do you have any brothers or sisters?” “My sister” R says, his voice is quiet and serious when he says this. “And what about your foster mom?” I ask. R gives a quick nod in agreement and stretches.

“And a foster dad?” I ask. “No” says R and he looks down, dismissing what I had asked. His defences have returned and are present. There is silence in the room. R had opened up and for the first session this was sufficient for the purpose of this song. I then move the session on to the next activity saying “Okay. Shall we play some drums to end?” “Where?” R says looking at me surprised and confused. I casually say “here” motioning towards the room and R responds with a confident “Ja.”

I decide to quickly recap what we have spoken about in our discussion, consolidating these characteristics of R. “Okay, so, let go over. So, we’ve got things you like to do, the song is going to be about you.” R nods enthusiastically as I read off the list. I continue saying “You

like to sing, play and go to school. Is there anything else you want to tell me about the R that you've drawn? "

R immediately responds, confidently at first but then he has to think and he pauses, "I like to be...um, how do you explain it...I like to be like, uh...no one must judge him, he just want to be him." As I write this down R stares at my hand intensely. "No one must judge him" I say in confirmation as I write it down. I look up at R and he nods at me casually and in affirmation.

"Cool!" I say and R casually nods at me and I nod at him, in acknowledgement of what we have written together and what R has shared with me. "Let's play some drums" I say to R and he gently nods in agreement, looking protective, on guard and with a neutral facial expression.

R-2

I ask R with energy if we should start with some drums. R, slouching back confidently in his chair, gives a slight nod in approval and then nonchalantly leans forward to place a drum in between his legs. He looks at me arrogantly, his head cocked up and eyebrow raised, as if I am taking long and he has been waiting for me so he can begin. I gently motion for him to begin. R wastes no time in beginning fervently. He plays a confident rhythm of, rhythm A. His playing is forte, strong and powerful, at a tempo of allegretto. He smiles an arrogant, cocky smile and then looks at me expectantly. I copy his rhythm and play it through with him twice, matching his intensity, tempo and dynamic. His smile disappears and concentration takes over.

I then change my playing and play a strong, base note in the middle of the djembe. R continues to play his rhythm on the side of the djembe, this time his dynamic has decreased to mezzo forte and his playing is not as strong and powerful, but the confidence remains. I am now playing a loud, confident, strong and powerful base note, matching the manner in which R began the improvisation, and then waiting while R continued to play his rhythm. R emphasises the main beat and together we play a strong main beat. R then continues with his rhythm, softer but confident.

He looks at me and smiles with satisfaction when we play the main beat together. It is strong and powerful. He then has the opportunity to improvise in between. He concentrates but shows enjoyment and confidence in his playing. He experiments with the rhythms but he remains grounded in the beat. The music is strong, loud, continuous and has a high energy level. R plays his rhythm once more and as he does I add in my own, three quaver, beat, which is loud, short and strong. We look at each other and R stops. I immediately stop with him and there is

silence, the silence is filled with emotion and connection and, almost, understanding of the music we had created together. R looks at me contently and smiles. He gives a short nod of acceptance, a joyful smile and makes meaningful eye contact.

R then quickly points with an extended arm to the mallet and asks inquisitively “what is that?!”

“Oh, this is for that” I say as I pick up the mallet and point it in the direction of the cymbal. R immediately grabs the mallet, a look of wonder on his face, his mouth slightly open and his eyes fixed on the cymbal. He hits the cymbal once with medium force, almost as if he is tentative of the instrument, and the sound rings out. R smiles, says “aaaaah” and stares at the mallet in wonder for a moment.

He then begins to hit his same rhythm on the djembe with the mallet. The rhythm is detached, strong and mezzo forte. R stares transfixed at the mallet as he plays, at first playing in the centre of the djembe and then with the stick section on the side to create a different sound. He experiments with curiosity at the different sounds he can produce from this new tool. As R plays his rhythm on the djembe with the mallet I copy his rhythm and play with him, at the same time, my music is strong and grounded, but not as loud as R. We are not perfectly in synch as R is slightly faster than I. As I am continuing with the rhythm R then hits the snare once, with force, and then the cymbal gently.

He says “ohm” in a meditation style and closes his eyes for a moment. I copy this saying “ohm” gently with my voice and holding the “mmm” for a moment. R looks in the distance as he listens intently to the sound of the cymbal ringing out and my voice holding the “ohm”. He then nods approvingly. R hits the mallet once in the centre of the djembe, sounding a loud, strong beat. I follow him by playing one beat in the centre of my djembe with my hand, imitating his loud, strong beat, a second after. R then plays one beat on the snare and then on the djembe. When he hits the djembe for the second time I match his playing, in timing, intensity, dynamic.

R and I hit the djembe at the same time, this time I played two beats and R played one. When R reached to play the snare, I reached to strum the guitar with one finger. R looked at me surprisingly. R then hit the djembe twice and I played it twice, we played on the djembe perfectly at the same time. A continuity began to develop in our experimentation of the different instruments, but there was a basic beat which grounded the music. R played the snare and I moved quickly to strum the guitar once and hit the tambourine before moving back to the djembe which we both hit, in time, twice. R watched the instruments I played and took this as license to experiment. He then played the djembe once, the snare once, the cymbal once and moved back to the djembe. While he played this, I played the djembe once, the guitar once,

the tambourine once and moved back to djembe. R looked up at me with surprise and joy, he smiled as we continued to play these different instruments together.

There was continuity and flow in the music, it was playful with a hint of experimentation as both R and I were finding our way in the music. The tambourine fell as I hit it for a third time and while this fell R played a quick five quaver rhythm on the djembe. He smiled and almost laughed as the tambourine fell. I copied his five-quaver rhythm on the edge of the djembe and R stopped playing, looking at the mallet. "Do you know what is this?" he asked inquisitively but with confidence in his voice. "A beater" I replied and I sat back in my chair. "Ja...now what's a marimba?" R asked and looked at me expectantly, as if I should know the answer because I am the music person. "Those are wooden and it looks like that" I said and I pointed to the glock so that he could have an understanding of the shape. As I spoke he played softly on the djembe with the mallet. His playing was more like fidgeting but with sound. "Ja and then you can play on it" and he made the gesture for playing a marimba. "Have you seen a marimba band" I asked and he immediately nodded that he had.

"R..." I began and he stopped fidgeting at looked at me expectantly and with curiosity. "Can you think of three words that describe you?" I sat forward and leant on the djembe as R thought. He sat forward and looked up at the sky "Me?" I affirmed this. "Three words?" He asked with a puzzled facial expression. He rolled the mallet from one hand to the other as he sat back in his chair. "Any three words" there was silence after I said this and so I continued. "Shall I give you three words that describe me? Will that help?" R nodded in agreement and watched me with a blank facial expression. "Um, happy..." R nodded enthusiastically when I said this. "helpful" R looked more serious, as if he was thinking. "and caring. I think those are three words that describe me. What three words can you think of that describe you?" R nodded with his entire body and played with the mallet, moving it from one hand to the other. "I like to laugh" he said, he smiled as he said this and made a gesture as if he was pointing with the mallet. I nodded affirmingly. "I like to help people" he said with more confidence in his voice, and a bigger smile, "and I like to do things." "Can you think of one word that means 'to do things'?" I asked him.

R held the mallet with both hands and looked down at it, he then looked up seriously and said "working" in a short manner and with confidence and strength in his voice. "working? Okay. Did you do any work this holiday?" I asked him. R nodded enthusiastically and said "I did work." He smiled and I laughed before asking him "what work?"

He dropped his eyes, no longer making eye contact and looked at the mallet, moving it between his hands in a fidgeting manner. "In the back of our yard" he said and he made eye contact. "In the garden?" I asked curiously and R nodded in agreement but not with too much

excitement or energy. “Did you plant things?” I asked and R said “Nooo” in a playful yet teasing manner. “Did you cut the grass?” I asked and R said yes in a whisper, dropping his eyes and looking at the mallet while he was fidgeting with it.

“What else did you do on holiday?” R looked up at me, closed his eyes and nodded once in a blaze manner, and said “just walking...walking with the dogs” he said this in a nonchalant manner, as if it was boring for him. “How many dogs do you have?” I asked and R responded with “three.” His demeanour was unenergetic, casual and bored, there was no longer a smile on his face and he made minimal eye contact. “What are their names?” I asked and then the smile returned. R continued to look down and said “Names?” and played two strong beats on the djembe with the mallet. “Do they have names?” I asked and he looked up at me and smiled a broader smile. “Ja” he said and he swung the mallet around in front of him. “Lily, Tiger and Roxy” he said this with affection in his voice, his voice was gentle and not as strong and confident as it had been earlier.

R played his original rhythm from the beginning of the session with the end of the mallet on the chair. He played it softly, almost as if he was simply fidgeting. I then said “okay” and turned to get an instrument. R then asked “is the song almost done?” He asked with a slight sense of urgency but mainly curiosity. “Oh, yes. I am glad you remembered about your song” I said in a surprised but happy manner and I turned to take out the chord and lyrics we had been working on.

R-3

R and I are sitting next to each other at the piano. I am playing the piano while R is playing the djembe. I am playing forte, strong and a four crotchet, pulsating rhythm on the piano, using the chord progression G# m, E, C# m, D# m. R is playing confidently and with emphasis a crotchet quaver quaver crotchet crotchet rhythm. R is looking at the djembe with a pensive expression but then he looks up at me and we make eye contact. Immediately R and I smile, happy smiles and our bodies move in time with the music. The music is lively, happy, energetic, rhythmical and loud.

We then look back at our instruments and begin singing the second verse of R’s song *Welcome to My Life*. R’s attention is now on the words in front of him which causes his beat to waver and become slightly fragmented as he concentrates on singing the words. I made sure to hold the beat and support the music by playing a strong rhythm and in turn R then found the beat again. He changed his rhythm to match mine, a four-crotchet rhythm, and he

played this at a mezzo forte level. R's voice was scratchy, mezzo piano and gentle, as he began singing but his voice then grew in confidence, became stronger and louder.

We sang the chorus of the song and as soon as the chorus began R's energy increased, he hit a forceful accented first note in his original rhythm. He did not sing but instead played. His music was confident, present and strong. He was fully engaged with the music and this was evident through his body language. R would lean forward on the first beat and rock his upper body, rhythmically and in time with the music. R showed investment and enjoyment in the music. I sang the chorus, my voice matching R in that it was strong, full, intense and mezzo forte. As I sang the third line of the chorus *And know what doesn't kill you, makes you want it more*, R sang with and stopped playing the djembe. His voice was loud and cracked as he pushed it to be louder. He sang sincerely with confidence, investment and joy. We made eye contact at this point and R smiled a big smile, which I returned. R only sang this line and then returned to playing djembe only, in the same confident and strong manner he had previously.

He continued to move with the music in lively manner. I then played the chord sequence only and R continued with his confident djembe playing. I kept the piano music strong and confident with a driving beat to match R's playing. R concentrated as he played, the smile had been replaced with concentration. The chord sequence ended and I played one final beat on G# m and looked at R to gauge where he wanted to take the music. R played a confident final beat at the same time as I played my final beat and we stopped together. I held my arms in the air for a moment and R and I made eye contact. This was a genuine and sincere moment which was evident in the look we gave each other when the music had ended. R smiled contently and I returned his smile. We sat for half a second in silence, enjoying the moment and the music we had created together.

R then wildly nodded his head in acknowledgement, he did not say anything, the silence remained for a few seconds. I returned his nod in the same manner of acknowledgement. "I like it" R finally said, breaking the silence, in a soft and gentle voice. "What do you think about when you sing this song?" I asked R. "Sho, a lot of people" R said in his normal speaking voice and with a shy smile. He looked at the words and thought deeply for a moment. "It feels so...relaxed" he continued nodding his head in agreement as he spoke. I smiled and repeated back to him "relaxed". We made eye contact and I asked "and does it feel nice to sing it?" placing my hand over my heart, indicating inside. "Ja" R gently whispered "I like it".

"Which people does it remind you of?" I asked softly. "My family" R said slightly louder than a whisper, his voice was gentle and sincere. "Okay...shall we continue with our other song?" I asked, referring to the third song we had begun writing in our previous session. "Ja, let's see what we have there" R said, his voice returning to his confident speaking voice. I got up to

move over to the table but R remained at the piano, playing separate notes in the same octave, in no particular melodic order, then changing the keyboard's sound to the drum kit and experimenting with the different sounds the different keys made. R did this in concentration.

"Is this song finished being written?" I asked R but he continued to experiment on the keyboard. "R?" I called his name and he immediately softly said "let me see." I repeated my question and R said "no" hanging on the word. "Come, let's sit here. Away from the distraction of the piano." R got up quickly and sat next to me at the table, making sure to switch the keyboard off before coming to sit down. "What is this now?" he asked curiously. "So, we said we were going to sing it to *Despacito* and so I brought the music with for that. So far, we have, I'm handsome, I care, I love, sometimes I'm moody, I like to work, I like to play, I'm careful."

I read this out slowly and then waited in the silence. R looked up at the ceiling thinking and digesting the words I had said. We sat in the silence, I waited expectantly for R to speak. R then looked at me, nodded in acknowledgment and agreement and said "What else...I don't like people who's like boring" as he spoke he motioned his hand to emphasise the word 'boring'. He watched me intently as I wrote down the words. "I don't like people who's moody" he continued, his voice confident and matter of fact.

After writing this down I repeated it back to him "So, you don't like people who are boring or people who's moody". He gently nodded his head then looked to the ceiling as he thought of what more to write. "I must think now" he said with a smile. I asked him "is there anything about yourself you wish you could change?" and I asked in it a casual manner, as we had been speaking about things he did not like in other people. He replied immediately with "I wish I could change my illness." He said this in a casual manner but watched me with baited breath as I wrote this down. "Why do you want to change your illness?" I asked and he immediately replied. "Because I don't like it. I can't do other stuff that the other kids are doing" he did not make eye contact with me and instead avoidantly watched the page I was writing on. Feeling this avoidance, I kept my gaze on the words I was writing.

I then looked up at him and he made brief eye contact with me, he did not smile and instead concern and worry were evident on his face. "Can we write *I don't like it?*" I asked and R said yes. "Maybe we can say *I want to do what others can do?*" I suggested and R immediately agreed, saying yes, nodding his head enthusiastically and gently rocking the upper half of his body. Even though R agreed he looked away and around the room while he agreed. He then turned back to look at me, as I was still writing, and said "but I can't". His voice was quiet but earnest. He watched me intensely as I wrote this down.

I sat for a moment and we both stared at the page, serious expressions on our faces. I then sat back and said “Nice, I think we have a song.” R hit his fist gently on the table and waited for a second before slowly and gently nodding his head. I pointed to the first verse saying “so that can be the one part” and then the second verse saying “and this can be the other”. R looked away briefly, nodding in agreement, but then back at the page as I began to speak again. “So, this part says all the things about you that you like and then the second part is all the things you don’t like.” R folded his arms on the table and stared at the page. He pursed his lips and then gently nodded, softly whispering “ja.”

“How long have you been sick for?” I asked R, feeling that he was ready to talk about his illness. “A long time” he sadly replied, shaking his head once as he said it.

R-4

R and I are sitting at the piano with all three of his songs printed out in front of us. R has chosen the order that we are going to play his songs in; his first composed song will be sung first, the last song he has composed about himself will be second and his favourite song, the second he composed, will be sung last. I have the guitar with me and R reaches for a djembe.

R places the djembe in front of him and picks up the mallet. “Here we go” I say and look towards our music. “From the top” I continue to say and R plays one loud beat and two soft quaver beats, before stopping and looking at the music. I look at him and begin playing the chord progression for the first song, a strumming pattern of down-down-down-down-up in the key of C major. R joins a second later with a four crotchet beat on the drum, his playing is slightly hesitant as he finds his place in the music and at a mezzo forte level. I play the C chord as an introduction before beginning the words. My music is stable, grounding and at a mezzo forte dynamic level.

R and I begin to sing the lyrics for the song, *we must care for one another*, and as we sing R’s playing grows in confidence and he begins to play louder, moving his body gently back and forth in time with the music. R’s voice is soft at first, as he is unsure of the words to the song, but as he remembers them his voice grows louder and more confident. I look at R with slight hesitation, gauging his music and his musical direction. His music grows in confidence and dynamic and I match this by increasing my dynamic level to forte and playing with a slight emphasis on my first strum in the strumming pattern, so as to ground the music.

As we sing the second line, *love one another*, R plays a slight variation of his beat by playfully playing four semiquavers and then three crotchets. He only does this once and then plays two crotchets and rests for two beats. R experiments with different rhythms and placing the hits on different beats in the rhythm. His playing is loud and confident and he uses his body language to emphasise these beats by moving forward and then back with each beat he plays. He then changes his beat again by playing on the djembe and then the table. When he plays on the table his playing is more tentative and is sounded at a mezzo piano level, whereas on the drum it is forte. He plays on the table and the djembe for the line, *your dreams will one day come true*.

We then reach the rap section of the song. I say “and now it’s the rap”. I hit the guitar at mezzo piano, holding back as I wait for R to begin and find his beat. R looks at the words and holds the mallet in the air, slightly unsure of how he is going to play and rap. He then continues to hit the djembe but only on the basic beat, no longer experimenting with rhythms and styles of playing. He fully immerses himself in the rap, changing his body movements to being quicker and back and forth with his arm, as if imitating a rapper seen on TV, he raps the verse.

As he raps we struggle to find each other in the beat, while I am holding on to the beat we had been using for the song, R’s beat is slightly slower but fragmented. I decrease my tempo and I manage to find his beat, following him and hitting the guitar, still at mezzo piano, in time with him. We get to the last line of the verse, which is our hook *if you know what I mean yeah yeah* and I join in rapping with R. Here we find synchrony again and R begins to play the basic beat on the djembe. Our music is in time with one another and there is continuity and connection in this. We both energetically rock back and forth in time with our music. R smiles but keeps his gaze on the words, I return his smile.

We then confidently go into the chorus together. R plays the basic beat loud and with confidence and I return to strumming the guitar, matching his loud confidence. R then experiments once more playing crotchet beats but one with the mallet on the djembe and one with his hand. When he plays with his hand it is soft but when he plays with the mallet it is loud. His body language does not indicate a change in effort for each beat and so his strength is what is determining the dynamic of the beat. As we come to the end of the chorus R playfully plays two quaver beats before I say “and rap” queuing him into the verse. He plays a loud beat on the djembe with the mallet as he begins to rap. His body movements return to that of a TV rapper and he raps with more confidence in his voice. I tap the guitar at a mezzo forte level, slightly louder than the first verse to adequately match R’s voice and his playing. He then holds the mallet with both hands as he raps the verse, concentrating on the words.

We rap the hook together, the tempo decreasing slightly and the rhythm attaining more of a groove. We move our bodies in time with the groove, gently back and forth. We both smile and then R points to the second song with his mallet saying “now it’s this one.” There is a moment of hesitation between us as we change the rhythm, tempo and key to begin the next song, *R*. I return to playing guitar, now in the key of E minor, and with a more staccato, double time, strumming pattern. R confidently and loudly plays the beat, four crotchet beats, he sings the words and his voice is softer and gentle. We sing at a mezzo piano level at first but then our dynamic increases to mezzo forte.

As we move into the second verse, *I don’t like people who’s moody*, I change my strumming to legato, increasing the richness and fullness of the sound. This in turn increases the intensity in the music. R’s voice gets softer and I hold the music by keeping my voice fully present and strong, continuing to sing as this may be difficult section for R to sing. R then stops singing altogether but continues to play confidently on the djembe with the mallet. Playing loud, hard and in a crotchet-quaver-quaver-crotchet-crotchet rhythm. He increases his body movement to more forceful rocks back and forth, moving his head from side to side and closing his eyes for a moment. I play the chord progression through without voice and the intensity in the music increases. R’s playing gets louder and I increase my dynamic to match his, we are now playing at forte. I sing the second line, *I don’t like people who are boring*, my voice keeping strong, holding and confident. R sings the word ‘boring’ and his gaze is constantly on the song, even though I am looking him. I sing the line, *I wish I could change my illness*, and as I sing this line R’s playing decreases in intensity, strength and dynamic to a mezzo piano/ piano level. He sings the last few words with me ‘change my illness’ and his voice is soft and withdrawn.

R’s beat becomes more consistent and grows in strength and dynamic, increasing to mezzo forte. Together we sing the line, *I don’t like it*, R’s voice remains small and soft. He then changes his beat as we sing the line, *I want to do what others can do*, to a loud and confident crotchet-rest-crotchet-rest rhythm. As we sing the word ‘it’ R looks down at the drum and hits it with intention, power and hard. He sings the word as he does but his voice is soft and withdrawn. We sing the line, *but I can’t*, and as we sing the word ‘can’t’ R looks up at me for the first time. He does not smile and there is a look of helplessness and sadness on his face.

I change my strumming pattern back to the staccato pattern for the chorus, *I don’t like it but I want to change it and be good and strong*. The energy quality changes in this section. R plays with determination and strength in a crotchet-quaver-quaver rhythm and we chant the words. R does not sing at first leaving me to sing the words. His body language is energetic, enthusiastic and driving as he rocks back and forth as he plays. I repeat the chorus and as I get to the line, *and be good and strong*, R begins to play in double time, increasing the dynamic

to fortissimo. I match him by increasing my dynamic to fortissimo. The intensity in the music increases with this change and the music has become filled with emotion and richness. I look at R and his body movements have become strong, confident, powerful and intentional, as if he is laying it all on the djembe.

I hold on the word 'strong' and let it fade out, keeping my voice strong and present. I then play the chord progression, without words, as an instrumental. R continues to play in double time, accenting the first beat with a fortississimo beat and the rest at fortissimo. I increase my dynamic level to fortissimo. We play the progression through once and then R plays an extremely loud and powerful final beat and I match this by strumming with all my strength and letting the E minor chord ring out. There was a release in this final beat from both R and I from all the built-up tension and intensity in the instrumental and the song in general.

R does not look at me and we sit for a second in silence as the chord rings out. R then points to the third song saying "now this." "Now the last one" I say back to him in a gentle, speaking voice. "Okay" R says and he helps me to move the other two songs off the piano so that I can play. He says "now it's my verse" and he changes the sound of the keyboard to piano for me. "Ready?" I ask and R plays a note closest to him on the keyboard to check that it is on the correct sound. I then begin playing mezzo forte on the keyboard in the key of G# minor the third song. My rhythm is a pulsating double time quaver pattern in 4/4. R plays confident and loud on the djembe in a crotchet-quaver-quaver rhythm. He looks at the song with concentration and does not make eye contact. I play the chord progression through once before we begin singing the first verse. As soon as we begin to sing R stops playing djembe and gives all his attention to singing the words. His voice is strained, mezzo forte and sincere. He sings the first line without playing but then begins to add the djembe, continuing with his rhythm.

The music for the verse is mezzo piano/ mezzo forte, legato, sincere and gentle. As we play the chorus R changes his rhythm to an experimentation between quavers and crotchets, always emphasising the main/ first beat and playing with confidence. We break, before going into the instrumental, perfectly in sync, and we then begin playing the instrumental. The music is pulsating, loud, strong and confident. R's body language returns to confident, powerful rocking back and forth and he emphasises the main beat at a fortissimo dynamic level. His playing is shorter, staccato, powerful and strong.

We move into the second verse and my playing becomes legato and sincere. R plays softer and adds quavers into his rhythm as he experiments, once again, with quavers and crotchets. His playing increases in dynamic to forte when we sing the line, *you are the most beautiful girl*, and this leads us into an even bigger dynamic increase and an increase in intensity into

the chorus. R's voice grows in confidence, strength and dynamic as he sings the chorus. I match my voice by keeping it strong and grounded. R shows investment in the music as he uses his whole body to play the djembe and sings as loud as he can, particularly the line, *makes you want it more, this is your life*. He emphasises the main beat with strength and power and rocks with intention back and forth in time with the music.

We break together perfectly in sync at the end of the chorus and go into one final instrumental. I sing the line, *this is your life*, on my own, as R chooses not to sing it with me, and we confidently and with purpose go into the final instrumental. R continues with his crotchet-quaver-quaver pattern, emphasising the main beat and playing with confidence, strength and power. I return to the pulsating rhythm which adequately matches R's playing as it is strong and driving. As I play the progression for a second time R changes the rhythm to crotchet-rest-crotchet-rest and I follow by breaking up my chord progression with rests, as he has done.

This creates a bit of space in the music as we bring the medley to an end. I watch intently R to gauge when he will end. He then sings *this is your life* and plays a final beat with emphasis and power. I catch him and play the final beat with him. He looks at me and smiles with confidence and satisfaction, I return his smile, and he nods his head once with intention and purpose saying "Ja!"

T

The nurse has just given T his chemo and T winces in pain as he chemo is injected into his right hand, the hand he was using to strum the guitar. T puts out his bottom lip in pain and I gently say "we can play softly." T looks at me and I repeat. His pain disappears as he adjusts his position on the guitar to better hold it. T hold his thumb and forefinger together and begins strumming the guitar, gently at first at a mezzo piano dynamic level but then this increases to mezzo forte. He strums downward, one strum for one beat, in 4/4. He looks at the guitar as he strums. I play gently on the snare drum, crotchet-crotchet-crotchet-rest. On the rest I hit the sticks together.

As T increases the dynamic I increase the dynamic of my playing. His playing is repetitive but he shows engagement and investment in his playing, looking down at the strings and then up the neck. As his playing is the same I experiment with different arrangements of playing on the snare and hitting the sticks together. T does not seem waivered by my experimentation and continues with his simple, repetitive strumming. There is a hint of a smile on his face and he looks down at the guitar.

The music is mezzo forte but empty. But then this changes as T begins to play slightly faster with his strumming and I follow by playing double time on the snare, increasing the fullness and intensity in the music. I watch T's playing so as to match and follow him, holding the musical space as he experiments with the guitar. He then slows down slightly and I return to playing my original rhythm with a rest. This added a different dynamic to the music, having the rest in with the repetitive guitar. T was completely involved with the guitar and did not look at me or acknowledge me for at least a minute. T plays the high E string only at a faster tempo and I match him by playing softly in double time on the snare.

T and I are separate in the music, he is fully engrossed in his playing and I am doing all the meeting and matching, reaching out to him but not receiving any response. His playing remains the same, a repetitive downward strumming pattern. I experiment with different variations of playing on the snare and hitting the sticks together, reaching out to T but making sure as to not push too much as it is his first session and this is his first improvisation. I wait and gauge his music, adding in variation to his repetitive grounding guitar.

I then play two crochets on the snare and then two crotchets on the side of the snare. T looks up at me and smiles a genuine, happy and sincere smile, making eye contact for a brief moment. I return his smile and he goes back to being engrossed by the guitar, still smiling. I change my playing to one beat on the side of the snare and one beat hitting the sticks together. But then I return to playing, gently, my original rhythm on the snare. I add my voice singing confidently but gently, at a low pitch and with presence. T smiles and looks at me as I sing, continuing to strum. I repeat my melody, in hopes T will catch on to it and sing, and at the third repetition T adds his voice. His voice is soft and raspy but present. T continues to play and sing, smiling as he does so and moving his head gently down with each main beat we play. We make eye contact and smile at one another as we sing the same melody. I then interchange between singing the original motif and then a short variation and back to the original motif. This makes T smile even more and he follows, continuing to sing.

Adding variation broke the repetitive nature of the music which was exacerbated by T's repetitive guitar. The music grew louder and I began to emphasise the main beat, moving my body forward with purpose to further emphasise it. T followed my action and began to move forward on the main beat and out his head down to further emphasise it for him. He began playing harder and the guitar fell off his lap onto the bed. He adjusted his body by leaning on his bed fully and crouching over the guitar. I copied his movement by crouching over the snare and decreasing the dynamic of my playing and singing. T then strummed a final chord and let it ring out. I stopped playing and looked at him, waiting and gauging where he was going to take the music.

T made brief eye contact, giggled and looked down. "Nice" I said as I sat back. "Do you like playing music?" I asked T as he continued to giggle and smile. He gave a gentle and deep nod in affirmation. He tapped the guitar and gently said "I like this." "Do you? Then maybe we can play more guitar and I can teach you some chords too" I said to T as he lay back in his bed, wincing as he moved his right arm where the chemo had been injected. He held onto the guitar as he lay back in his bed but he looked at me expectantly.

"Would you like to daw for a little bit?" I asked him, intending to lead him into drawing a self-portrait, and T nodded his head immediately in agreement. T continued to strum the guitar with enthusiasm as I set up the materials. "Can we move these things from your table and then you can draw on here?" I asked as his bedside table was filled with chips and cooldrink and water. "Ja" he said gently, continuing to strum on the guitar. He watched me as I moved everything around, setting up the space for him to draw. As I set up the space I sang the melodic motifs we had improvised on, keeping engaged with his music he was creating even though we were moving on to a different aspect of the session. T looked at me and smiled. The music was casual, mezzo piano, legato and gentle.

I moved the percussion instruments to the end of his bed and lay out the arts materials. He stopped playing for a moment to investigate what I had put before him. "Everything you could need" I said to him, "are you ready?". T then began playing a rhythm on the guitar, lively and with energy and so instead of carrying on with the intention of the session I sat down and played with him. T began singing words but they were soft and almost inaudible. I leaned forward to listen to his words. I played on the djembe, a basic beat slightly softer than his playing, so as to ground his music and engage with him and his song. His voice grew louder and more confident. The music was mezzo forte, rich and full. T made eye contact with me and looked confidently away continuing to sing, leading the music and genuinely encompassing this role of being the leader.

I smiled at him and copied his rhythm on the djembe, increasing the dynamic of my playing to mezzo forte. T was singing the lyrics *when I call his name, then Jesus was, every tongue confess, every knee shall bow, when I call his name, then Jesus was*. His voice was no longer raspy but instead confident yet gentle.

He played with intention, purpose and conviction on the guitar. Confidently leading the music. I followed and gave the leadership to him, following his rhythm, dynamic and tempo. I did not sing with as I could not properly hear the words and provided him with the opportunity to sing solo and be supported in the music. I followed and then T strummed a final chord, looking up at me with a sincere look on his face. I smiled at him and stopped playing when he did.

F

F hits the drum sticks confidently together four times, counting us into the music. F confidently begins playing loudly on the snare and I follow, strumming a rhythm in 4/4; *crotchet-quaver-quaver-crotchet-crotchet*. F played on the snare drum rhythmically and with confidence. I played C maj on the guitar, matching his rhythm and playing at mezzo forte. F played allegro with force and energy, and this increased as he continued to play.

F smiles slightly as he plays. We played this synchronously twice. I played F maj on the guitar and shortly after F added in a hit on the cymbal. The rhythm fluctuates as F unsurely switches his arms over one another so that he can more comfortably play the snare and the cymbal in the rhythm. I said "Nice" in an affirming tone and F coyly smiled. F hit the cymbal tentatively at first but then with more strength as he wanted a louder sound. F loudly and confidently hit one beat on the snare and paused, and I mirrored by hitting the guitar strings down and wait expectantly for a moment.

F made brief eye contact to gauge my response. He gave a brief smile in recognition of what I had done, almost as if to commend me. He played a slightly varied rhythm from the original and I followed on guitar with C maj. F played with more of a groove and the tempo slowed down to andantino and we continued to play the same rhythm synchronously together in this groove, I changed between C maj and F maj. F watched the beaters and instruments as he played them with joy, wonder and excitement.

F made eye contact with me to express this joy and wonder, non-verbally, and he smiled at me as we played together, I followed his lead and matched each beat with a strum on the guitar, my music was grounding and structured, so as to reinforce his rhythm.

F then suddenly pulled back and stopped, lying flatter on his back, as oppose to leaning to play the instruments, and held the sticks above his chest, expectantly waiting, almost as if he had to think for a moment. I waited for a brief moment and then sang and strummed two notes, calling F back into the music. I paused and waited for him to continue the music, gauging where he was musically and physically. He responded by firmly hitting one stick on the snare in a basic beat and I took this as the cue to continue and sang a short melody from the chord progression I was playing.

F played tentatively on the snare drum at first but then returned to his confident playing. He began playing a faster rhythm; *crotchet-quaver-quaver-quaver-quaver-quaver-crotchet-quaver*, still in 4/4. The music was present and confident for a moment but then it began to fluctuate and fragment as F played the snare and cymbal at the same time in a slower rhythm.

It took a few moments before we found each other in the music and returned to the basic beat, now at a slower tempo. In that time, I sang and attempted to match him but for a few moments we did not synch. We then found each other in the music and I played slightly faster to match F's tempo. There was a sudden pause as F realised he had a different beater to play with and he picked up the softer mallet to experiment on the instruments.

He experimented by play in the middle of the snare drum, tentatively at first but then his beat grew with confidence and dynamic, crotchet- crotchet - crotchet - crotchet -quaver-quaver-minim. I followed his new rhythm on guitar, increasing my dynamic to mezzo forte. F then experimented and played on the cymbal with the fur mallet and the drum stick on the snare, the same rhythm. His music was now mezzo forte, due to the fur on the mallet, but the confidence and strength remained. I struggled to follow him, as his rhythm fluctuated due to changing instruments, and therefore accompanied with simple down strumming to his beat, so as to ground and hold the experimentation.

F played this beat once and then shook his head in disappointment at the muffled sound caused by the mallet, putting down the fur mallet and picking up the other drum stick. The fur mallet had made the sound too soft for his liking. F confidently played loud and rhythmically on the snare and cymbal at the same time in his original rhythm. I followed and sang the rhythm on 'dum ba-dum'. The music was loud and chaotic, yet still rhythmical and filled with emotion. F looked happy and confident as he played the rhythm, now in a slight groove.

F then grimaced and slowly put his sticks up on either side of his body. I stopped immediately, following his lead. F whimpered as I sang 'ah', I paused to gauge his reaction but immediately checked in with him asking if he was okay. F irritably shook his right arm in the air twice with a grimace on his face. I asked if it was "a bit too much?" gauging whether he was in need of attention or if he needed a break, as this had been our agreement from the start, and he nodded, indicating that he needed a break. "Too much energy at one time?" I said in a gentle manner and F gently nodded in agreement, putting his stick down and holding it across his chest.

I gauged whether it was okay to continue but F seemed to be okay and so I decided to strum softly and sang the melody I had been singing. I sang in a gentle manner, constantly gauging F's response and needs. F looked at me expectantly, as if to ask what we were going to do next, and I asked him "can you sing me a song?" He coyly shook his head and looked down, shy, but then he smiled.

"Do you not know any songs?" I asked, trying to direct the music in his preferential direction, and he shook his head in embarrassment, but his shy smile remained. "One song?" I asked

in disbelief that he knew no songs. F avoidantly looked up at the ceiling, smiled and shook his head. “No?” I asked in disbelief, again, but F shook his head, still continuing to smile.

F looked at me with a smile. I was about to suggest a song and F’s facial expression changed, the smile being replaced with a grimace, slight discomfort evident on his face. He looked away and I noticed his breathing became shallow. He lightly coughed once and I immediately asked if he was okay and if he needed anything but he shook his head. “Are you fine?” I asked concerned. He firmly nodded his head, indicating he was fine, and touched his chest as he looked for his juice bottle. He quickly took a sip of his juice and I sat back and casually said “I also have...if you like gospel music, do you go to church?” He gently nodded in agreement. I continued “Is it? Which church do you go to?” and F shook his head, indicating that he didn’t know which church.

“Do you only like gospel music?” and F gave a small, brief nod of his head. “Don’t you like Rock N Roll, or Kwaito?” I curiously asked. F gently nodded his head in agreement to kwaito, his breathing remained shallow. “Do you like Kwaito?” F nodded with more enthusiasm. “Do you like Mandoza?” F nodded but then grimaced as he coughed and shook his head slightly. I asked him if he was feeling okay and he gently shook his head, a pained expression now evident on his face, and touched his chest.

I urgently asked him if he was okay and if he would like to take a little break and he coughed, with more force and he moved slightly to his side, indicating he wanted to take a break. He lay with his hand on his chest and he continued to shallowly breathe. He then shook his head in frustration with himself and said “uh-uh”. “Are you not feeling well?” I asked, gauging whether he needed assistance or whether he just needed a break from the physical activity we had been doing, and he shook his head, looking down at his bed and making minimal eye contact.

I checked in with him asking him “do you want to carry on? Are you okay to carry on just now, we can stop for a bit?” and he nodded his head in agreement and grimaced. I assured him by saying “we will go at your pace. Is it sore? What do you need?” F gently nodded and he grimaced in pain. He rubbed his chest and coughed. He then reached his arm onto the bed to gently hold two egg shakers. I asked him if he wanted the bucket but he firmly shook his head indicating no and I reminded him that he must let me know if he does need it. F nodded his head in recognition.

He brought the egg shakers up and firmly held an egg shaker in each hand. He began softly and gently shake them in a rapid tempo. I matched by playing rapidly and softly on the high string of the guitar. F watched me as I played, sussing out what I was doing. He then quickly shook his head and said “uh-uh”, grimaced and closed his eyes. “No?” I asked and he

continued to shake his head, still holding the egg shakers. I briefly continued to play gently on the high string and then F mumbled softly "I can't breathe", his tone was casual. I immediately stopped and asked him to repeat himself.

"You can't breathe?" I asked for clarification and he pointed to his chest, coughed and nodded in affirmation, still holding the egg shakers. I urgently asked "Must I call the nurse?" F nodded but then shook his head, changing his mind and saying "My mom." I quickly left the room to go get her and F nodded, looking down and not making eye contact.

He continued to softly, gently cough, yet he still continued holding the egg shakers. F looked down at his bed, a sullen expression on his face, still clutching the egg shakers.

G (R Song 1)

We must care for one another

Love one another

We must keep on dreaming

Your dreams will one day come true

Red devil wants to be himself

Nobody must judge me

I wanna judge myself

If you know what I mean

You must love your family

You must love them more than anything in this world

You must love your sister more

Cause she is your blood

If you know what I mean

Yeah, Yeah

If you know what I mean

Yeah, Yeah

H (R Song 3)

I'm handsome,

I care

I love, Sometimes I'm moody, yeah

I like to work and help out

I like to play

I don't like people who are boring

I don't like people whose moody

I wish I could change my illness

I don't like it

I want to do what others can do

But I can't

I don't like it

But I want to want to change it

Oh yeah,

And be good and strong

APPENDIX G

Coding

A (R-1)	Code
<p>[R and I are sitting, fairly close, next to each other at a desk. R is in a wheelchair while I sit in a chair. R finishes off his drawing, a self-portrait, with a pencil. R is closed off and does not make eye contact.]</p> <p>["Can you tell me anything about him?" I ask R in a gentle speaking voice, breaking the silence in the room.] [R looks at me questioningly then his drawing and back at me.] [He smiles coyly, unsure of what I am wanting from him.] [I then ask him further "Do you want to talk about him?" in a questioning but relaxed tone, not wanting to pry if he was not ready to share.]</p> <p>["Um...about him?" R responds, seemingly still unsure, although he shyly smiles.] ["Ja, and about you. About the you that you drew" I continue to say. R sighs despairingly, unsure of what to say and avoiding the question, but then looks at me and shyly smiles. He shakes his head, looking down at the desk. He is avoidant, defensive and closed off.] [I sense this and change line of questioning, staying more concrete and giving the questions more direction, instead of being open. "I see he is walking." I say to R.]</p> <p>[R nods his head, matter of factly and in agreement.] [His face is blank, showing the expression of 'so what'. There is palpable silence in the room.] [I continue with my concrete questioning, gauging that this is the best approach, "Is he going somewhere?"] [R immediately responds by nodding enthusiastically and in affirmation.] ["Where is he going?" I ask and he responds with "To school."]</p> <p>["Do you go to school while you're here?" I ask] [and R immediately looks down at the table, despondent and</p>	<p>A1- Resistant to making contact</p> <p>A2- Tension in the silence</p> <p>A3- questioning and unsure</p> <p>A4- timid</p> <p>A5- timid</p> <p>A6- defensive</p> <p>A7- casual agreement</p> <p>A8- interactional tension due to resistance</p> <p>A9- enthusiastic engagement</p> <p>A10- sharing</p> <p>A11- despondent</p>

<p>slowly shakes his head.] [I steer the conversation in a positive direction and ask “Do you like going to school?”] [and R nods, resting his head on his arm, seemingly uninterested, guarded] [and a hint of boredom.] [“For the learning or for your friends?” I ask and R responds] [promptly with “To learn.”]</p>	<p>A12- uninterested and defensive A13- bored A14- sharing</p>
<p>[I ask him “What’s your favourite subject?”, keeping the conversation concrete as I can sense the defences are present. And R responds with “Math” in a casual manner, not making eye contact and fidgeting with the drawing. “Maths? Mine too.” I say this, finding a commonality between us. R nods and continues to fidget with the page.] [He sits back and looks at me expectantly. There is silence once more in the room.]</p>	<p>A15- casual yet defensive</p>
<p>[Sensing that this is not a topic he wants to discuss further I change the direction of the session “So, we are going to be writing a song.”] [R gives a slight, affirmative nod and seems interested as I pick up a piece of paper and a pen. He watches my movements, not wanting to show too much interest but just enough for it to be noticed by me.] [“I would like us to write down some words, about you, now, and the you that you drew” my voice now carrying a bit of weight and intention, expecting more of a response from R.]</p>	<p>A16- interactional tension due to resistance A17- interest</p>
<p>[R looks down at the page and then at me and then back down at the page, unsure and slightly confused.] [I elaborate and explain further by saying “So, what can you tell me that stands out about you, and the you on the page?”]</p>	<p>A18- confused and unsure</p>
<p>[R understands and immediately responds, in a gentle speaking voice, “I like to sing.” I affirm his contribution by repeating it back to him “You like to sing, and what else?”] [R fidgets with the pencils and give a coy, shy smile.] [“He like to sing” he says and points to his</p>	<p>A19- sharing A20- shy</p>

drawing. R does not make eye contact, only looking at the picture and then to the pencils he is fidgeting with.]
 ["And to walk?" I ask prompting him to speak about himself by speaking about the picture. R casually nods and continues to fidget with the pencils.]

[R continues by saying "and I like to play", his facial expression is neutral and he is casual in his mannerisms. "He likes to play and walk" I say as I am writing this down, "And go to school?" R gives a gentle nod in affirmation and fidgets, looking down at his drawing, not making eye contact.] [Feeling he is ready to slightly open up emotionally I ask, "What type of type of person are you? Like the R on the page. Are you a happy person, a sad person, an angry person...?" R immediately responds with a smile and says "Happy person!"] [R then accidentally knocks a pencil that it rolls off the table. He watches it in astonishment as one drops and then two more. He smiles and finds it funny. I count "1, 2, 3" as they fall on the floor. R looks at me with a joyful smile.]

["And the music that I played? Did you like that music?" I ask gauging his musical interests. "I like that music!" R says with conviction and a confident head nod.] ["Chris Brown. So, when we write our song I think it should definitely be a hip hop song?" I ask him and he responds with "Yep!" casually nodding his head, R then looks at me, continuing to fidget with the pencils.] [I keep the topic of conversation on the music and our intention for the song we are going to be writing, asking "Shall we rap in it?" R likes this idea and smiles coyly, he then looks at me then down to the pencil he is playing with. He has become shy.]

["Like why, what?" he shyly asks while smiling a nervous smile. "We can make it up together" I tell him encouragingly, trying to ease the obvious nervousness.] [R then changes the direction/ intention of the exercise

- A21- distancing
- A22- casual yet defensive
- A23- concrete sharing
- A24- deeper emotional sharing
- A25- playful
- A26- confident
- A27- casual and expectant
- A28- shy
- A29- nervously shy

and says “We must sing a song and we must learn it”, wanting to learn a precomposed song. But I respond by saying “We are going to make the song together. We are going to write all the words and put the music to it. You are going to write the words. And then I will write the music for it.” [R looks down, uncertain about this task,] [but he slowly nods as he thinks about what is being asked of him.] [R avoids the task again by saying “I must sing the words. You write them.” But when I said “You’re going to write them as well.”] [R complained and said “Nooo” He said it in a playful manner but his voice is not convincing as a proper rejection of the idea.]

[I encouragingly say to him “We will write it together.” But R diverts the task, smiling nervously and saying “I want to sing, I don’t want to write it.”] [I prompt him no this and ask “Why not?” and he responds with “I don’t like to write.”] [As he says this he does not make eye contact, he seems uneasy in this task being asked of him. “You don’t like to write. Well what if I write it down and you can tell me what to write?” I compromise with him.] [R nods wearily but accepting the task,] [the smile disappearing from his face. He looks down at his page and begins to play with the hair on his head, which is short.]

["So, what is our song going to be about? We have these things that you like to do; to sing, to play, to walk, school, happy and you like hip hop. What else can it be about?" He responds confidently, yet with an upper inflection in his voice "About me." [I affirm his contribution "About you, ja." R then whispers "And my family." R watches me intently as I write down his family.] [I prompt him by asking "Who is in your family?" and R responds with a bashful smile saying "A lot of people".] [I prompt him further "A lot of people? Do you have any brothers or sisters?" "My sister" R says, his voice is quiet and serious

A30- assertive yet avoidant

A31- unsure

A32- tentative agreement

A33- avoidant

A34- playful avoidance

A35- nervous rejection

A36- voicing his feelings/
assertive

A37- weary acceptance

A38- defensive

A39- confident

A40- serious

A41- shy/ bashful

A42- serious

<p>when he says this.] ["And what about your foster mom?" I ask. R gives a quick nod in agreement and stretches.]</p>	<p>A43- casual agreement</p>
<p>["And a foster dad?" I ask. "No" says R and he looks down, dismissing what I had asked.] [His defences have returned and are present. There is silence in the room.]</p>	<p>A44- dismissive A45- defensive</p>
<p>[R had opened up and for the first session this was sufficient for the purpose of this song.] [I then move the session on to the next activity saying "Okay. Shall we play some drums to end?"] ["Where?" R says looking at me surprised and confused.] [I casually say "here" motioning towards the room and R responds with a confident "Ja."]</p>	<p>A46- slight opening up A47- confused A48- confident</p>
<p>[I decide to quickly recap what we have spoken about in our discussion, consolidating these characteristics of R. "Okay, so, let go over. So, we've got things you like to do, the song is going to be about you." [R nods enthusiastically as I read off the list. I continue saying "You like to sing, play and go to school. Is there anything else you want to tell me about the R that you've drawn?"]</p>	<p>A49- enthusiastic engagement</p>
<p>[R immediately responds, confidently at first] [but then he has to think and he pauses, "I like to be...um, how do you explain it...I like to be like, uh...no one must judge him, he just want to be him."] [As I write this down R stares at my hand intensely.] ["No one must judge him" I say in confirmation as I write it down. I look up at R and he nods at me casually and in affirmation.</p>	<p>A50- confident A51- deeper emotional sharing A52- serious A53- casual agreement</p>
<p>"Cool!" I say and R casually nods at me and I nod at him, in acknowledgement of what we have written together and what R has shared with me. "Let's play some drums" I say to R and he gently nods in agreement,] [looking protective, on guard in his body language and facial expression.]</p>	<p>A54- defensive and on guard</p>

B (R-2)	
<p>[I ask R with energy if we should start with some drums.] [R, slouching back confidently in his chair, gives a slight nod in approval and then nonchalantly leans forward to place a drum in between his legs.] [He looks at me arrogantly, his head cocked up and eyebrow raised, as if I am taking long and he has been waiting for me so he can begin. I gently motion for him to begin.] [R wastes no time in beginning fervently.] [He plays a confident rhythm of, rhythm A.] [His playing is forte, strong and powerful, at a tempo of allegretto.] [He smiles an arrogant, cocky smile and then looks at me expectantly. I copy his rhythm and play it through with him twice, matching his intensity, tempo and dynamic.] [His smile disappears and concentration takes over.]</p> <p>[I then change my playing and play a strong, bass note in the middle of the djembe. R continues to play his rhythm on the side of the djembe,] [this time his dynamic has decreased to mezzo forte and his playing is not as strong and powerful, but the confidence remains.] [I am now playing a loud, confident, strong and powerful base note, matching the manner in which R began the improvisation, and then waiting while R continued to play his rhythm.] [R emphasises the main beat and together we play a strong main beat.] [R then continues with his rhythm, softer but confident.]</p> <p>[He looks at me and smiles with satisfaction when we play he main beat together.] [It is strong and powerful.] [He then has the opportunity to improvise in between.] [He concentrates but shows enjoyment and confidence in his playing. He experiments with the rhythms] [but he remains grounded in the beat.] [The music is strong, loud, continuous and has a high energy level.] [R plays his rhythm once more and as he does I add in my own, three quaver, beat, which is loud, short and strong.] [We</p>	<p>B1- casual</p> <p>B2- confident and excited</p> <p>B3- enthusiasm</p> <p>B4- confident</p> <p>B5- powerful</p> <p>B6- confident arrogance</p> <p>B7- concentration</p> <p>B8- confident</p> <p>B9- unity and developing relationship</p> <p>B10- beginnings of reciprocity</p> <p>B11- developing relationship, closeness</p> <p>B12- powerful</p> <p>B13- creative</p> <p>B14- meaningful creativity</p> <p>B15- grounded</p>

<p>look at each other] [and R stops.] [I immediately stop with him] [and there is silence, the silence is filled with emotion and connection and, almost, understanding of the music we had created together.] [R looks at me contently and smiles.] [He gives a short nod of acceptance, a joyful smile and makes meaningful eye contact.]</p>	<p>B16- high energy, confident B17- interaction B18- agency B19- emotional connection and developing relationship</p>
<p>[R then quickly points with an extended arm to the mallet and asks inquisitively “what is that?!”]</p>	<p>B20- content B21- meaningful interaction</p>
<p>[“Oh, this is for that” I say as I pick up the mallet and point it in the direction of the cymbal.] [R immediately grabs the mallet, a look of wonder on his face, his mouth slightly open and his eyes fixed on the cymbal.] [He hits the cymbal once with medium force, almost as if he is tentative of the instrument, and the sound rings out.] [R smiles, says “aaaaah” and stares at the mallet in wonder for a moment.]</p>	<p>B22- curios B23- experimenting B24- tentative B25- instrument discovery</p>
<p>[He then begins to hit his same rhythm on the djembe with the mallet. The rhythm is detached, strong and mezzo forte.] [R stares transfixed at the mallet as he plays, at first playing in the centre of the djembe and then with the stick section on the side to create a different sound. He experiments with curiosity at the different sounds he can produce from this new tool.] [As R plays his rhythm on the djembe with the mallet I copy his rhythm and play with him, at the same time, my music is strong and grounded, but not as loud as R.] [We are not perfectly in synch as R is slightly faster than I.] [As I am continuing with the rhythm R then hits the snare once, with force, and then the cymbal gently.]</p>	<p>B26- strong B27- curious experimenting B28- not in synch due to excitement</p>
<p>[He says “ohm” in a meditation style and closes his eyes for a moment. I copy this saying “ohm” gently with my voice and holding the “mmm” for a moment.] [R looks in the distance as he listens intently to the sound of the</p>	<p>B29- variation in playing B30- playful B31- contemplative</p>

cymbal ringing out and my voice holding the “ohm”.] [He then nods approvingly.] [R hits the mallet once in the centre of the djembe, sounding a loud, strong beat. I follow him by playing one beat in the centre of my djembe with my hand, imitating his loud, strong beat, a second after.] [R then plays one beat on the snare and then on the djembe. When he hits the djembe for the second time I match his playing, in timing, intensity, dynamic.

R and I hit the djembe at the same time, this time I played two beats and R played one. When R reached to play the snare, I reached to strum the guitar with one finger.] [R looked at me surprisingly.] [R then hit the djembe twice and I played it twice, we played on the djembe perfectly at the same time.] [A continuity began to develop in our experimentation of the different instruments, but there was a basic beat which grounded the music.] [R played the snare and I moved quickly to strum the guitar once and hit the tambourine before moving back to the djembe which we both hit, in time, twice. R watched the instruments I played and took this as license to experiment. He then played the djembe once, the snare once, the cymbal once and moved back to the djembe. While he played this, I played the djembe once, the guitar once, the tambourine once and moved back to djembe.] [R looked up at me with surprise and joy, he smiled as we continued to play these different instruments together.]

[There was continuity and flow in the music, it was playful with a hint of experimentation as both R and I were finding our way in the music.] [The tambourine fell as I hit it for a third time and while this fell R played a quick five quaver rhythm on the djembe. He smiled and almost laughed as the tambourine fell. I copied his five-quaver rhythm on the edge of the djembe] [and R stopped playing, looking at the mallet. “Do you know what is this?”

B32- acceptance of interaction

B33- strong and confident

B34- experimenting, yet distracted

B35- surprised at therapist's holding

B36- imitation

B37- continuity due to relational interaction

B38- experimentation through distraction

B39- content in turning distraction into musical experimentation

B40- playful experimentation

B41- child-like and innovative

B42- confident questioning

<p>he asked inquisitively but with confidence in his voice. “A beater” I replied and I sat back in my chair. “Ja...now what’s a marimba?” R asked and looked at me expectantly, as if I should know the answer because I am the music person.] [“Those are wooden and it looks like that” I said and I pointed to the glock so that he could have an understanding of the shape.] [As I spoke he played softly on the djembe with the mallet. His playing was more like fidgeting but with sound.] [“Ja and then you can play on it” and he made the gesture for playing a marimba. “Have you seen a marimba band” I asked and he immediately nodded that he had.]</p> <p>[“R...” I began and he stopped fidgeting at looked at me expectantly and with curiosity.] [“Can you think of three words that describe you?” I sat forward and leant on the djembe] [as R thought. He sat forward and looked up at the sky “Me?” I affirmed this. “Three words?” He asked with a puzzled facial expression. He rolled the mallet from one hand to the other as he sat back in his chair.] [“Any three words” there was silence after I said this and so I continued. “Shall I give you three words that describe me? Will that help?”] [R nodded in agreement and watched me with a blank facial expression.] [“Um, happy...” R nodded enthusiastically when I said this.] [“helpful” R looked more serious, as if he was thinking.] [“and caring. I think those are three words that describe me. What three words can you think of that describe you?”] [R nodded with his entire body] [and played with the mallet, moving it from one hand to the other.] [“I like to laugh” he said,] [he smiled as he said this and made a gesture as if he was pointing with the mallet. I nodded affirmingly.] [“I like to help people”] [he said with more confidence in his voice, and a bigger smile,] [“and I like to do things.”] [“Can you think of one word that means ‘to do things’?” I asked him.]</p>	<p>B43- distracted fidgeting</p> <p>B44- listening and understanding</p> <p>B45- curiosity</p> <p>B46- nervous due to expectation /guarded questioning</p> <p>B47- inquisitive</p> <p>B48- understanding</p> <p>B49- deeper exploration</p> <p>B50- enthusiastic agreement</p> <p>B51- distracted</p> <p>B52- happy</p> <p>B53- guarded sharing</p> <p>B54- caring and helpful</p>
--	--

<p>[R held the mallet with both hands and looked down at it, he then looked up seriously] [and said “working” in a short manner and with confidence and strength in his voice.] [“working? Okay. Did you do any work this holiday?” I asked him.] [R nodded enthusiastically and said “I did work.” He smiled and I laughed before asking him “what work?”]</p>	<p>B55- confident sharing B56- worker B57- deeper emotional exploration B58- confident sharing</p>
<p>[He dropped his eyes, no longer making eye contact and looked at the mallet,] [moving it between his hands in a fidgeting manner.] [“In the back of our yard” he said and he made eye contact.] [“In the garden?” I asked curiously and R nodded in agreement but not with too much excitement or energy.] [“Did you plant things?” I asked and] [R said “Nooo” in a playful yet teasing manner.] [“Did you cut the grass?” I asked and R said yes in a whisper,] [dropping his eyes and looking at the mallet while he was fidgeting with it.]</p>	<p>B59- enthusiastic and confident sharing about work B60- guarded when thinking of home B61- fidgeting B62- sharing B63- casual B64- teasing and playful</p>
<p>[“What else did you do on holiday?”] [R looked up at me, closed his eyes and nodded once in a blaze manner], [and said “just walking...walking with the dogs” he said this in a nonchalant manner, as if it was boring for him.] [“How many dogs do you have?” I asked and R responded with “three.”] [His demeanour was unenergetic, casual and bored,] [there was no longer a smile on his face and he made minimal eye contact.] [“What are their names?” I asked and] [then the smile returned.] [R continued to look down and said “Names?” and played two strong beats on the djembe with the mallet. “Do they have names?” I asked and he looked up at me and smiled a broader smile. “Ja” he said and he swung the mallet around in front of him.] [“Lily, Tiger and Roxy” he said this with affection in his voice,] [his voice was gentle and not as strong and confident as it had been earlier.]</p>	<p>B65- quiet sharing B66- avoidant fidgeting B67- blaze annoyance B68- casual sharing B69- concrete sharing B70- unenergetic and casual B71- avoidant/ guarded/ bored B72- smile due to happy association B73- energetic, enthusiastic sharing</p>

<p>[R played his original rhythm from the beginning of the session with the end of the mallet on the chair. He played it softly, almost as if he was simply fidgeting.] [I then said “okay” and turned to get an instrument.] [R then asked “is the song almost done?”] [He asked with a slight sense of urgency but mainly curiosity.] [“Oh, yes. I am glad you remembered about your song” I said in a surprised but happy manner and I turned to take out the chord and lyrics we had been working on.]</p>	<p>B74- affection B75- gentle tone of voice B76- fidgeting B77- agency in remembering B78- urgent curiosity</p>
<p>C (R-3)</p>	
<p>[R and I are sitting next to each other at the piano. I am playing the piano while R is playing the djembe. I am playing forte, strong and a four crotchet, pulsating rhythm on the piano, using the chord progression G# m, E, C# m, D# m.] [R is playing confidently and with emphasis a crotchet-quaver-quaver-crotchet-crotchet rhythm.] [R is looking at the djembe with a pensive expression] [but then he looks up at me and we make eye contact. Immediately R and I smile, happy smiles and our bodies move in time with the music.] [The music is lively, happy, energetic, rhythmical and loud.]</p> <p>[We then look back at our instruments and begin singing the second verse of R’s song <i>Welcome to My Life</i>.] [R’s attention is now on the words in front of him which causes his beat to waver and become slightly fragmented as he concentrates on singing the words.] [I made sure to hold the beat and support the music by playing a strong rhythm and in turn R then found the beat again.] [He changed his rhythm to match mine, a four-crotchet rhythm,] [and he played this at a mezzo forte level.] [R’s voice was scratchy, mezzo piano and gentle, as he began singing] [but his voice then grew in confidence, became stronger and louder.]</p>	<p>C1- confident C2- thoughtful C3- meaningful connection through eye contact and music C4- lively, energetic, rhythmical, happy music C5- fragmentation due to concentration showing investment in the song C6- interpersonal awareness C7- energetic music C8- gentle voice C9- confident, strong voice</p>

<p>[We sang the chorus of the song and as soon as the chorus began R's energy increased, he hit a forceful accented first note in his original rhythm.] [He did not sing but instead played. His music was confident, present and strong.] [He was fully engaged with the music and this was evident through his body language. R would lean forward on the first beat and rock his upper body, rhythmically and in time with the music.] [R showed investment and enjoyment in the music.] [I sang the chorus, my voice matching R in that it was strong, full, intense and mezzo forte. As I sang the third line of the chorus <i>And know what doesn't kill you, makes you want it more,</i>] [R sang with and stopped playing the djembe. His voice was loud and cracked as he pushed it to be louder.] [He sang sincerely with confidence, investment and joy.] [We made eye contact at this point and R smiled a big smile, which I returned.] [R only sang this line and then returned to playing djembe only, in the same confident and strong manner he had previously.]</p> <p>[He continued to move with the music in lively manner.] [I then played the chord sequence only] [and R continued with his confident djembe playing.] [I kept the piano music strong and confident with a driving beat to match R's playing.] [R concentrated as he played, the smile had been replaced with concentration.] [The chord sequence ended and I played one final beat on G# m and looked at R to gauge where he wanted to take the music.] [R played a confident final beat at the same time as I played my final beat and we stopped together.] [I held my arms in the air for a moment and R and I made eye contact.] [This was a genuine and sincere moment which was evident in the look we gave each other when the music had ended. R smiled contently and I returned his smile.] [We sat for half a second in silence, enjoying the moment and the music we had created together.]</p>	<p>C10- energy and force</p> <p>C11- confident</p> <p>C12- actively engaged in music-making</p> <p>C13- investment and enjoyment</p> <p>C14- pushing his voice due to investment in song</p> <p>C15- sincere and confident</p> <p>C16- meaningful contact</p> <p>C17- strong and confident</p> <p>C18- lively and energetic</p> <p>C19- confident</p> <p>C20- concentration</p> <p>C21-musical connection and contact</p> <p>C22- personal connection and contact</p> <p>C23- genuine and sincere meaningful moment</p>
--	---

<p>[R then wildly nodded his head in acknowledgement, he did not say anything, the silence remained for a few seconds. I returned his nod in the same manner of acknowledgement. "I like it"] [R finally said, breaking the silence, in a soft and gentle voice.] ["What do you think about when you sing this song?" I asked R.] ["Sho, a lot of people" R said in his normal speaking voice] [and with a shy smile.] [He looked at the words and thought deeply for a moment.] ["It feels so...relaxed" he continued nodding his head in agreement as he spoke.] [I smiled and repeated back to him "relaxed". We made eye contact and I asked "and does it feel nice to sing it?" placing my hand over my heart, indicating inside. "Ja" R gently whispered "I like it".</p>	<p>C24- relationship and mutuality C25- contentment C26- gentle and sincere C27- emotional connection to music C28- shy C29- emotional exploration C30- relaxed</p>
<p>"Which people does it remind you of?" I asked softly. "My family" R said slightly louder than a whisper, his voice was gentle and sincere.] ["Okay...shall we continue with our other song?" I asked, referring to the third song we had begun writing in our previous session.] ["Ja, let's see what we have there" R said, his voice returning to his confident speaking voice.] [I got up to move over to the table but R remained at the piano, playing separate notes in the same octave, in no particular melodic order,] [then changing the keyboard's sound to the drum kit and experimenting with the different sounds the different keys made. R did this in concentration.]</p>	<p>C31- gentle and sincere C32- confident C33- distractable C34-concentrating experimenting</p>
<p>["Is this song finished being written?" I asked R but he continued to experiment on the keyboard.] ["R?" I called his name and he immediately softly said "let me see." I repeated my question and R said "no" hanging on the word.] ["Come, let's sit here. Away from the distraction of the piano."] [R got up quickly and sat next to me at the table, making sure to switch the keyboard off before coming to sit down.] ["What is this now?" he asked curiously.] ["So, we said we were going to sing it to</p>	<p>C35- agency C36- responsible in turning off C37- playful curiosity</p>

<p><i>Despacito</i> and so I brought the music with for that.] [So far, we have, I'm handsome, I care, I love, sometimes I'm moody, I like to work, I like to play, I'm careful.]"</p>	<p>C38- positive aspects of R</p>
<p>[I read this out slowly and then waited in the silence.] [R looked up at the ceiling thinking and digesting the words I had said. We sat in the silence, I waited expectantly for R to speak.] [R then looked at me, nodded in acknowledgment and agreement] [and said "What else...I don't like people who's like boring" as he spoke he motioned his hand to emphasise the word 'boring'.] [He watched me intently as I wrote down the words.] ["I don't like people who's moody" he continued, his voice confident and matter of fact.]</p>	<p>C39- casual agreement C40- deeper exploration C41- intense investment C42- confident sharing</p>
<p>[After writing this down I repeated it back to him "So, you don't like people who are boring or people who's moody".] [He gently nodded his head] [then looked to the ceiling as he thought of what more to write. "I must think now" he said with a smile.] [I asked him "is there anything about yourself you wish you could change?" and I asked in it a casual manner, as we had been speaking about things he did not like in other people.] [He replied immediately] [with "I wish I could change my illness."] [He said this in a casual manner but watched me with baited breath as I wrote this down.] ["Why do you want to change your illness?" I asked] [and he immediately replied. "Because I don't like it.] [I can't do other stuff that the other kids are doing"] [he did not make eye contact with me and instead avoidantly watched the page I was writing on. Feeling this avoidance,] [I kept my gaze on the words I was writing.]</p>	<p>C43- gentle agreement C44- guarded deflection C45- immediacy in answering C46- I wish I could change my illness. C47- casual yet defensive C48- deep emotional sharing C49- resentment C50- avoidant behaviour</p>
<p>[I then looked up at him and he made brief eye contact with me, he did not smile and instead concern and worry were evident on his face.] ["Can we write <i>I don't like it?</i>" I asked and R said yes. "Maybe we can say <i>I want to do what others can do?</i>" I suggested and R immediately</p>	<p>C51- concern and worry</p>

<p>agreed, saying yes, nodding his head enthusiastically and gently rocking the upper half of his body. Even though R agreed he looked away and around the room while he agreed.] [He then turned back to look at me, as I was still writing, and said “but I can’t”.] [His voice was quiet but earnest. He watched me intensely as I wrote this down.]</p> <p>[I sat for a moment and we both stared at the page, serious expressions on our faces. I then sat back and said “Nice, I think we have a song.”] [R hit his fist gently on the table and waited for a second before slowly and gently nodding his head.] [I pointed to the first verse saying “so that can be the one part” and then the second verse saying “and this can be the other”.] [R looked away briefly, nodding in agreement, but then back at the page as I began to speak again.] [“So, this part says all the things about you that you like and then the second part is all the things you don’t like.” R folded his arms on the table and stared at the page. He pursed his lips and then gently nodded, softly whispering “ja.”]</p> <p>[“How long have you been sick for?” I asked R, feeling that he was ready to talk about his illness.] [“A long time” he sadly replied, shaking his head once as he said it.]</p>	<p>C52- distant agreement</p> <p>C53- helplessness</p> <p>C54- earnest and quiet</p> <p>C55- serious emotional connection</p> <p>C56- forceful agreement</p> <p>C57- casual agreement</p> <p>C58- closed off</p> <p>C59- sadness</p>
<p>D (R-4)</p>	
<p>[R and I are sitting at the piano with all three of his songs printed out in front of us. R has chosen the order that we are going to play his songs in; his first composed song will be sung first, the last song he has composed about himself will be second and his favourite song, the second he composed, will be sung last. I have the guitar with me and R reaches for a djembe.]</p> <p>[R places the djembe in front of him and picks up the mallet. “Here we go” I say and look towards our music. “From the top” I continue to say and] [R plays one loud</p>	<p>D1- agency</p> <p>D2- confident entry</p>

<p>beat and two soft quaver beats,] [before stopping and looking at the music.] [I look at him and begin playing the chord progression for the first song, a strumming pattern of down-down-down-down-up in the key of C major.] [R joins a second later with a four crotchet beat on the drum, his playing is slightly hesitant as he finds his place in the music and at a mezzo forte level.] [I play the C chord as an introduction before beginning the words. My music is stable, grounding and at a mezzo forte dynamic level.]</p>	<p>D3- self-doubt</p> <p>D4- hesitant</p>
<p>[R and I begin to sing the lyrics for the song, <i>we must care for one another</i>, and] [as we sing R's playing grows in confidence and he begins to play louder, moving his body gently back and forth in time with the music.] [R's voice is soft at first, as he is unsure of the words to the song,] [but as he remembers them his voice grows louder and more confident.] [I look at R with slight hesitation, gauging his music and his musical direction.] [His music grows in confidence and dynamic] [and I match this by increasing my dynamic level to forte and playing with a slight emphasis on my first strum in the strumming pattern, so as to ground the music.]</p>	<p>D5- engagement</p> <p>D6- discovering confidence</p> <p>D7- unsure and hesitant</p> <p>D8- confident</p> <p>D9- increasing confidence</p>
<p>[As we sing the second line, <i>love one another</i>, R plays a slight variation of his beat by playfully playing four semiquavers and then three crotchets. He only does this once and then plays two crotchets and rests for two beats. R experiments with different rhythms and placing the hits on different beats in the rhythm.] [His playing is loud and confident and he uses his body language to emphasise these beats by moving forward and then back with each beat he plays.] [He then changes his beat again by playing on the djembe and then the table.] [When he plays on the table his playing is more tentative] [and is sounded at a mezzo piano level, whereas on the drum it is forte. He plays on the table and the djembe for the line, <i>your dreams will one day come true</i>.]</p>	<p>D10- experimentation and variation</p> <p>D11- confident and invested</p> <p>D12- variation</p> <p>D13- tentative towards new sounds</p> <p>D14- variation</p>

[We then reach the rap section of the song. I say “and now it’s the rap”. I hit the guitar at mezzo piano, holding back as I wait for r to begin and find his beat.] [R looks at the words and holds the mallet in the air, slightly unsure of how he is going to play and rap.] [He then continues to hit the djembe but only on the basic beat, no longer experimenting with rhythms and styles of playing.] [He fully immerses himself in the rap, changing his body movements to being quicker and back and forth with his arm, as if imitating a rapper seen on TV, he raps the verse.]

[As he raps we struggle to find each other in the beat, while I am holding on to the beat we had been using for the song, R’s beat is slightly slower but fragmented.] [I decrease my tempo and I manage to find his beat, following him and hitting the guitar, still at mezzo piano, in time with him.] [We get to the last line of the verse, which is our hook *if you know what I mean yeah yeah* and I join in rapping with R.] [Here we find synchrony again and R begins to play the basic beat on the djembe.] [Our music is in time with one another and there is continuity and connection in this.] [We both energetically rock back and forth in time with our music.] [R smiles but keeps his gaze on the words,] [I return his smile.]

[We then confidently go into the chorus together.] [R plays the basic beat loud and with confidence] [and I return to strumming the guitar, matching his loud confidence.] [R then experiments once more playing crotchet beats but one with the mallet on the djembe and one with his hand.] [When he plays with his hand it is soft but when he plays with the mallet it is loud.] [His body language does not indicate a change in effort for each beat and so his strength is what is determining the dynamic of the beat.] [As we come to the end of the chorus R playfully plays two quaver beats] [before I say

- D15- hesitant and unsure
- D16- grounding himself
- D17- imitation and full investment
- D18- fragmentation due to hesitance
- D19- disconnection
- D20- finding each other in the music, synchrony
- D21- mutuality in the music
- D22- high energy
- D23- guarded connection
- D24- mutual confidence
- D25- leading the music
- D26- experimenting
- D27- variation
- D28- control
- D29- playful, child-like

<p>“and rap” queuing him into the verse.] [He plays a loud beat on the djembe with the mallet as he begins to rap.] [His body movements return to that of a TV rapper and he raps with more confidence in his voice.] [I tap the guitar at a mezzo forte level, slightly louder than the first verse to adequately match R’s voice and his playing.] [He then holds the mallet with both hands as he raps the verse, concentrating on the words.]</p>	<p>D30- confident leadership D31- full investment D32- concentration</p>
<p>[We rap the hook together, the tempo decreasing slightly and the rhythm attaining more of a groove.] [We move our bodies in time with the groove, gently back and forth. We both smile] [and then R points to the second song with his mallet saying “now it’s this one.”] [There is a moment of hesitation between us as we change the rhythm, tempo and key to begin the next song, <i>R.</i>] [I return to playing guitar, now in the key of E minor, and with a more staccato, double time, strumming pattern.] [R confidently and loudly plays the beat, four crotchet beats,] [he sings the words and his voice is softer and gentle.] [We sing at a mezzo piano level at first but then our dynamic increases to mezzo forte.]</p>	<p>D33- attuning to one another D34- mutuality D35- agency D36- hesitation and we adjust D37- confident music D38- gentle voice D39- increase in dynamic as emotion builds</p>
<p>[As we move into the second verse, <i>I don’t like people who’s moody</i>, I change my strumming to legato, increasing the richness and fullness of the sound. This in turn increases the intensity in the music.] [R’s voice gets softer] [and I hold the music by keeping my voice fully present and strong, continuing to sing] [as this may be difficult section for R to sing.] [R then stops singing altogether] [but continues to play confidently on the djembe with the mallet.] [Playing loud, hard and in a crotchet-quaver-quaver-crotchet-crotchet rhythm.] [He increases his body movement to more forceful rocks back and forth, moving his head from side to side and closing his eyes for a moment.] [I play the chord progression through without voice and the intensity in the</p>	<p>D40- increase richness to match intensity of emotion D41- withdraws due to increase of emotional intensity D42- difficult emotions D43- defensively withdraws vocally D44- confident musically D45- forceful</p>

<p>music increases.] [R's playing gets louder and I increase my dynamic to match his, we are now playing at forte.] [I sing the second line, <i>I don't like people who are boring</i>, my voice keeping strong, holding and confident.] [R sings the word 'boring' and his gaze is constantly on the song, even though I am looking him.] [I sing the line, <i>I wish I could change my illness</i>,] [and as I sing this line R's playing decreases in intensity, strength and dynamic to a mezzo piano/ piano level.] [He sings the last few words with me 'change my illness'] [and his voice is soft and withdrawn.]</p>	<p>D46- fully engaged in the music</p>
<p>[R's beat becomes more consistent and grows in strength and dynamic, increasing to mezzo forte.] [Together we sing the line, <i>I don't like it</i>, R's voice remains small and soft.] [He then changes his beat as we sing the line, <i>I want to do what others can do</i>, to a loud and confident crotchet-rest-crotchet-rest rhythm.] [As we sing the word 'it' R looks down at the drum and hits it with intention, power and hard.] [He sings the word as he does but his voice is soft and withdrawn.] [We sing the line, <i>but I can't</i>, and as we sing the word 'can't' R looks up at me for the first time.] [He does not smile and there is a look of helplessness and sadness on his face.]</p>	<p>D47- emotional intensity increases</p>
<p>[I change my strumming pattern back to the staccato pattern for the chorus, <i>I don't like it but I want to change it and be good and strong</i>.] [The energy quality changes in this section.] [R plays with determination and strength in a crotchet-quaver-quaver rhythm and we chant the words.] [R does not sing at first leaving me to sing the words.] [His body language is energetic, enthusiastic and driving as he rocks back and forth as he plays.] [I repeat the chorus and as I get to the line, <i>and be good and strong</i>, R begins to play in double time, increasing the dynamic to fortissimo.] [I match him by increasing my dynamic to fortissimo. The intensity in the music</p>	<p>D48- dynamic increases</p>
	<p>D49- avoidant</p>
	<p>D50- withdraws due to emotional intensity</p>
	<p>D51- emotional connection, preservation of life</p>
	<p>D52- slightly guarded, difficult emotion</p>
	<p>D53- strong emotional investment</p>
	<p>D54- withdrawn due to deeper emotional connection</p>
	<p>D55- powerful due to deeper emotional connection</p>
	<p>D56- intent power</p>
	<p>D57- still vocally withdrawn</p>
	<p>D58- musical and personal interaction/ connection</p>
	<p>D59- helpless sadness</p>
	<p>D60- emotional shift</p>

<p>increases with this change and the music has become filled with emotion and richness.] [I look at R and his body movements have become strong, confident, powerful and intentional, as if he is laying it all on the djembe.]</p>	D61- determination and strength
<p>[I hold on the word 'strong' and let it fade out, keeping my voice strong and present. I then play the chord progression, without words, as an instrumental.] [R continues to play in double time, accenting the first beat with a fortississimo beat and the rest at fortissimo.] [I increase my dynamic level to fortissimo.] [We play the progression through once and then R plays an extremely loud and powerful final beat] [and I match this by strumming with all my strength and letting the E minor chord ring out.] [There was a release in this final beat from both R and I from all the built-up tension and intensity in the instrumental and the song in general.]</p>	<p>D62- vocally withdrawn</p> <p>D63- invested musically</p> <p>D64- musical increase due to emotional connection</p> <p>D65- emotional, full, rich</p> <p>D66- sincerely strong and powerful</p> <p>D67- fully invested</p> <p>D68- loud and powerful</p>
<p>[R does not look at me and we sit for a second in silence as the chord rings out.] [R then points to the third song saying "now this."] ["Now the last one" I say back to him in a gentle, speaking voice.] ["Okay" R says and he helps me to move the other two songs off the piano so that I can play.] [He says "now it's my verse"] [and he changes the sound of the keyboard to piano for me.] ["Ready?" I ask and R plays a note closest to him on the keyboard to check that it is on the correct sound.] [I then begin playing mezzo forte on the keyboard in the key of G# minor the third song. My rhythm is a pulsating double time quaver pattern in 4/4.] [R plays confident and loud on the djembe in a crotchet-quaver-quaver rhythm.] [He looks at the song with concentration and does not make eye contact.] [I play the chord progression through once before we begin singing the first verse.] [As soon as we begin to sing R stops playing djembe and gives all his attention to singing the words.] [His voice is strained, mezzo forte and sincere.] [He sings the first line without playing] [but</p>	<p>D69- release from built up emotional tension</p> <p>D70- interpersonal emotional connection in the silence</p> <p>D71- agency</p> <p>D72- helpful</p> <p>D73- ownership</p> <p>D74- helpful assistance</p> <p>D75- confident</p> <p>D76- concentration</p> <p>D77- full investment in the lyrics</p> <p>D78- strained due to sincerity</p>

<p>then begins to add the djembe, continuing with his rhythm.]</p>	<p>D79- vocally focused</p>
<p>[The music for the verse is mezzo piano/ mezzo forte, legato, sincere and gentle.] [As we play the chorus R changes his rhythm to an experimentation between quavers and crotchets,] [always emphasising the main/ first beat and playing with confidence.] [We break, before going into the instrumental, perfectly in sync,] [and we then begin playing the instrumental.] [The music is pulsating, loud, strong and confident. R's body language returns to confident, powerful rocking back and forth] [and he emphasises the main beat at a fortissimo dynamic level.] [His playing is shorter, staccato, powerful and strong.]</p>	<p>D80- musical investment</p> <p>D81- sincere</p> <p>D82- variation</p> <p>D83- confidently leading</p> <p>D84- musically synchronous due to interpersonal relationship</p> <p>D85- strong</p> <p>D86- confidently leading</p> <p>D87- powerful</p>
<p>[We move into the second verse and my playing becomes legato and sincere.] [R plays softer and adds quavers into his rhythm as he experiments, once again, with quavers and crotchets.] [His playing increases in dynamic to forte when we sing the line, <i>you are the most beautiful girl,</i>] [and this leads us into an even bigger dynamic increase and an increase in intensity into the chorus.] [R's voice grows in confidence, strength and dynamic as he sings the chorus.] [I match my voice by keeping it strong and grounded.] [R shows investment in the music as he uses his whole body to play the djembe and sings as loud as he can, particularly the line, <i>makes you want it more, this is your life.</i>] [He emphasises the main beat with strength and power and rocks with intention back and forth in time with the music.]</p>	<p>D88- variation</p> <p>D89- emotional investment</p> <p>D90- increase in intensity due to emotional investment</p> <p>D91- confident and strong</p> <p>D92- fully invested</p> <p>D93- powerful leading</p>
<p>[We break together perfectly in sync at the end of the chorus and go into one final instrumental.] [I sing the line, <i>this is your life,</i> on my own, as R chooses not to sing it with me,] [and we confidently and with purpose go into the final instrumental.] [R continues with his crotchet-quaver-quaver pattern, emphasising the main beat and</p>	<p>D94- musically synchronous due to interpersonal relationship</p> <p>D95- vocal agency</p> <p>D96- purposefully</p>

<p>playing with confidence, strength and power.] [I return to the pulsating rhythm which adequately matches R's playing as it is strong and driving.] [As I play the progression for a second time] [R changes the rhythm to crotchet-rest-crotchet-rest] [and I follow by breaking up my chord progression with rests, as he has done.]</p> <p>[This creates a bit of space in the music as we bring the medley to an end.] [I watch intently R to gauge when he will end.] [He then sings <i>this is your life</i> and plays a final beat with emphasis and power.] [I catch him and play the final beat with him.] [He looks at me and smiles with confidence and satisfaction,] [I return his smile,] [and he nods his head once with intention and purpose saying "Ja!"]</p>	<p>D97- confident leading</p> <p>D98- strong and driving</p> <p>D99- variation</p> <p>D100- musical space to indicate ending</p> <p>D101- agency and investment in leading the end</p> <p>D102- sincere confidence and satisfaction</p> <p>D103- acknowledgement of emotional music</p>
<p>E (T)</p>	
<p>[The nurse has just given T his chemo] [and T winces in pain as his chemo is injected into his right hand, the hand he was using to strum the guitar.] [T puts out his bottom lip in pain] [and I gently say "we can play softly."] [T looks at me and I repeat.] [His pain disappears as he adjusts his position on the guitar to better hold it]. [T hold his thumb and forefinger together and begins strumming the guitar,] [gently at first at a mezzo piano dynamic level but then this increases to mezzo forte.] [He strums downward, one strum for one beat, in 4/4. He looks at the guitar as he strums.] [I play gently on the snare drum, crotchet-crotchet-crotchet-rest. On the rest I hit the sticks together.</p> <p>As T increases the dynamic I increase the dynamic of my playing.] [His playing is repetitive but he shows engagement and investment in his playing, looking down at the strings and then up the neck.] [As his playing is the same I experiment with different arrangements of playing</p>	<p>E1- evident pain</p> <p>E2- expression on pain</p> <p>E3- eye contact</p> <p>E4- interest in music despite pain</p> <p>E5- imitation of guitarist</p> <p>E6- increase in dynamic due to increase in comfort</p> <p>E7- musical investment</p> <p>E8- repetitive yet investment</p>

on the snare and hitting the sticks together.] [T does not seem waivered by my experimentation and continues with his simple, repetitive strumming.] [There is a hint of a smile on his face and he looks down at the guitar.]

[The music is mezzo forte but empty.] [But then this changes as T begins to play slightly faster with his strumming] [and I follow by playing double time on the snare, increasing the fullness and intensity in the music.] [I watch T's playing so as to match and follow him, holding the musical space as [he experiments with the guitar. He then slows down slightly] [and I return to playing my original rhythm with a rest. This added a different dynamic to the music, having the rest in with the repetitive guitar.] [T was completely involved with the guitar and did not look at me or acknowledge me for at least a minute.] [T plays the high E strong only at a faster tempo] [and I match him by playing softly in double time on the snare.]

[T and I are separate in the music, he is fully engrossed in his playing and I am doing all the meeting and matching, reaching out to him but not receiving any response.] [His playing remains the same, a repetitive downward strumming pattern.] [I experiment with different variations of playing on the snare and hitting the sticks together, reaching out to T but making sure as to not push too much as it is his first session and this is his first improvisation. I wait and gauge his music, adding in variation to his repetitive grounding guitar.

I then play two crochets on the snare and then two crotchets on the side of the snare.] [T looks up at me and smiles a genuine, happy and sincere smile, making eye contact for a brief moment.] [I return his smile and he goes back to being engrossed by the guitar, still smiling.] [I change my playing to one beat on the side of the snare and one beat hitting the sticks together. But then I return

E9- lack of interpersonal awareness/ focus on intrapersonal

E10- enjoyment in the music

E11- music is loud but empty

E12- agency in musical change

E13- increase in intensity

E14- curious experimenting

E15- lack of interpersonal awareness, focus on intrapersonal

E16- increase in musical intention

E17- lack of interpersonal connection

E18- rigid

E19- genuine and sincere personal interaction

E20- self-involved

<p>to playing, gently, my original rhythm on the snare. I add my voice singing confidently but gently, at a low pitch and with presence.] [T smiles and looks at me as I sing, continuing to strum.] [I repeat my melody, in hopes T will catch on to it and sing], [and at the third repetition T adds his voice.] [His voice is soft and raspy but present.] [T continues to play and sing, smiling as he does so and moving his head gently down with each main beat we play.] [We make eye contact and smile at one another as we sing the same melody.] [I then interchange between singing the original motif and then a short variation and back to the original motif.] [This makes T smile even more and he follows, continuing to sing.]</p> <p>[Adding variation broke the repetitive nature of the music which was exacerbated by T's repetitive guitar.] [The music grew louder] [and I began to emphasise the main beat, moving my body forward with purpose to further emphasise it.] [T followed my action and began to move forward on the main beat and put his head down to further emphasise it for him. He began playing harder and the guitar fell off his lap onto the bed.] [He adjusted his body by leaning on his bed fully and crouching over the guitar.] [I copied his movement by crouching over the snare and decreasing the dynamic of my playing and singing.] [T then strummed a final chord and let it ring out.] [I stopped playing and looked at him, waiting and gauging where he was going to take the music.]</p> <p>[T made brief eye contact, giggled and looked down.] ["Nice" I said as I sat back. "Do you like playing music?" I asked T as he continued to giggle and smile.] [He gave a gentle and deep nod in affirmation.] [He tapped the guitar and gently said "I like this." ["Do you? Then maybe we can play more guitar and I can teach you some chords too" I said] [to T as he lay back in his bed, wincing as he moved his right arm where the chemo had been</p>	<p>E21- showing awareness of others</p> <p>E22- agency in singing</p> <p>E23- soft but present vocal</p> <p>E24- enjoyment and engagement with the music</p> <p>E25- personal interaction</p> <p>E26- increasing awareness of others</p> <p>E27- increase in dynamic</p> <p>E28- musical investment</p> <p>E29- deeper emotional investment in the music</p> <p>E30- autonomy</p> <p>E31- personal/ meaningful interaction</p> <p>E32- agency in affirmation</p> <p>E33- investment in an instrument</p> <p>E34- evident pain</p>
---	---

<p>injected.] [He held onto the guitar as he lay back in his bed but he looked at me expectantly.]</p> <p>["Would you like to daw for a little bit?" I asked him, intending to lead him into drawing a self-portrait,] [and T nodded his head immediately in agreement.] [T continued to strum the guitar with enthusiasm as I set up the materials.] ["Can we move these things from your table and then you can draw on here?" I asked as his bedside table was filled with chips and cooldrink and water.] ["Ja" he said gently, continuing to strum on the guitar.] [He watched me as I moved everything around, setting up the space for him to draw.] [As I set up the space I sang the melodic motifs we had improvised on,] [keeping engaged with his music he was creating even though we were moving on to a different aspect of the session.] [T looked at me and smiled.] [The music was casual, mezzo piano, legato and gentle.]</p> <p>[I moved the percussion instruments to the end of his bed and lay out the arts materials.] [He stopped playing for a moment to investigate what I had put before him.] ["Everything you could need" I said to him, "are you ready?"] [T then began playing a rhythm on the guitar, lively and with energy] [and so instead of carrying on with the intention of the session I sat down and played with him.] [T began singing words but they were soft and almost inaudible.] [I leaned forward to listen to his words. I played on the djembe, a basic beat slightly softer than his playing, so as to ground his music and engage with him and his song.] [His voice grew louder and more confident.] [The music was mezzo forte, rich and full.] [T made eye contact with me] [and looked confidently away continuing to sing, leading the music and genuinely encompassing this role of being the leader.]</p> <p>[I smiled at him and copied his rhythm on the djembe, increasing the dynamic of my playing to mezzo forte.] [T</p>	<p>E35- attachment to the music</p> <p>E36- open to new experiences</p> <p>E37- attachment to the music</p> <p>E38- continuing the music</p> <p>E39- curious observation</p> <p>E40- constant musical engagement as opposed to verbal engagement</p> <p>E41- sincere personal interaction</p> <p>E42- gentle music</p> <p>E43- curious observation</p> <p>E44- energetic music, dismissive of new experience</p> <p>E45- agency</p> <p>E46- increasing confidence</p> <p>E47- rich music</p> <p>E48- autonomy/ taking ownership of leading</p> <p>E49- agency in singing a familiar song</p>
---	--

<p>was singing the lyrics] [<i>when I call his name, then Jesus was, every tongue confess, every knee shall bow, when I call his name, then Jesus was.</i>] [His voice was no longer raspy but instead confident yet gentle.]</p> <p>[He played with intention, purpose and conviction on the guitar.] [Confidently leading the music.] [I followed and gave the leadership to him, following his rhythm, dynamic and tempo. I did not sing with as I could not properly hear the words and provided him with the opportunity to sing solo and be supported in the music. I followed] [and then T strummed a final chord,] [looking up at me with a sincere look on his face.] [I smiled at him and stopped playing when he did.]</p>	<p>E50 – religious value system</p> <p>E51- gentle and confident</p> <p>E52- purposeful music</p> <p>E53- confidently leading</p> <p>E54- agency in ending</p> <p>E55- sincere personal interaction</p>
<p>F (F)</p>	
<p>[F hits the drum sticks confidently together four times, counting us into the music.] [F confidently begins playing loudly on the snare and I follow, strumming a rhythm in 4/4; <i>crotchet-quaver-quaver-crotchet-crotchet.</i>] [F played on the snare drum rhythmically and with confidence.] [I played C maj on the guitar, matching his rhythm and playing at mezzo forte.] [F played allegro with force and energy, and this increased as he continued to play.]</p> <p>[F smiles slightly as he plays.] [We played this synchronously twice.] [I played F maj on the guitar] [and shortly after F added in a hit on the cymbal.] [The rhythm fluctuates as F unsurely switches his arms over one another so that he can more comfortably play the snare and the cymbal in the rhythm.] [I said “Nice” in an affirming tone] [and F coyly smiled.] [F hit the cymbal tentatively at first] [but then with more strength as he wanted a louder sound.] [F loudly and confidently hit one beat on the snare and paused,] [and I mirrored by hitting</p>	<p>F1- confident musical entry</p> <p>F2- choice of loud, big musical instruments</p> <p>F3- rhythmical confidence</p> <p>F4- allegro, force and energy</p> <p>F5- enjoyment in the music</p> <p>F6- synchronous interaction</p> <p>F7- experimentation</p> <p>F8- fluctuation due to unsurity</p> <p>F9- coy smile</p> <p>F10- tentative at first</p>

<p>the guitar strings down and wait expectantly for a moment.]</p>	<p>F11- strength increases with comfort</p>
<p>[F made brief eye contact to gauge my response.] [He gave a brief smile in recognition of what I had done, almost as if to commend me.] [He played a slightly varied rhythm from the original] [and I followed on guitar with C maj.] [F played with more of a groove and the tempo slowed down to andantino] [and we continued to play the same rhythm synchronously together in this groove,] [I changed between C maj and F maj.] [F watched the beaters and instruments as he played them with joy, wonder and excitement.]</p>	<p>F12- confident in musical changes F13- personal interaction F14- agency in affirmation F15- variation F16- slower music with a groove F17- meaningful musical interaction</p>
<p>[F made eye contact with me to express this joy and wonder, non-verbally, and he smiled at me as we played together,] [I followed his lead and matched each beat with a strum on the guitar, my music was grounding and structured, so as to reinforce his rhythm.]</p>	<p>F18- joy in the music F19- meaningful interaction</p>
<p>[F then suddenly pulled back and stopped, lying flatter on his back, as oppose to leaning to play the instruments, and held the sticks above his chest, expectantly waiting, almost as if he had to think for a moment.] [I waited for a brief moment and then sang and strummed two notes, calling F back into the music. I paused and waited for him to continue the music, gauging where he was musically and physically.] [He responded by firmly hitting one stick on the snare in a basic beat] [and I took this as the cue to continue and sang a short melody from the chord progression I was playing.]</p>	<p>F20- sudden stop due to illness and overexertion F21- firm musical intention</p>
<p>[F played tentatively on the snare drum at first] [but then returned to his confident playing.] [He began playing a faster rhythm; crotchet-quaver-quaver-quaver-quaver-quaver-crotchet-quaver, still in 4/4.] [The music was present and confident] [for a moment but then it began to fluctuate and fragment as F played the snare and</p>	<p>F22- tentative at first F23- confident F24- agency in musical change F25- confident and present</p>

cymbal at the same time in a slower rhythm.] [It took a few moments before we found each other in the music and returned to the basic beat, now at a slower tempo.] [In that time, I sang and attempted to match him but for a few moments we did not synch.] [We then found each other in the music and I played slightly faster to match F's tempo.] [There was a sudden pause as F realised he had a different beater to play with and he picked up the softer mallet to experiment on the instruments.]

[He experimented by play in the middle of the snare drum, tentatively at first] [but then his beat grew with confidence and dynamic, crotchet- crotchet - crotchet - crotchet -quaver-quaver-minim.] [I followed his new rhythm on guitar, increasing my dynamic to mezzo forte.] [F then experimented and played on the cymbal with the fur mallet and the drum stick on the snare, the same rhythm.] [His music was now mezzo forte, due to the fur on the mallet, but the confidence and strength remained.] [I struggled to follow him, as his rhythm fluctuated due to changing instruments, and therefore accompanied with simple down strumming to his beat, so as to ground and hold the experimentation.]

[F played this beat once and then shook his head in disappointment at the muffled sound caused by the mallet, putting down the fur mallet and picking up the other drum stick. The fur mallet had made the sound too soft for his liking.] [F confidently played loud and rhythmically on the snare and cymbal at the same time in his original rhythm.] [I followed and sang the rhythm on 'dum ba-dum'.] [The music was loud and chaotic, yet still rhythmical and filled with emotion.] [F looked happy and confident as he played the rhythm, now in a slight groove.]

[F then grimaced and slowly put his sticks up on either side of his body.] [I stopped immediately, following his

F26- fragmented and slow

F27- finding each other in the music

F28- matching

F29- increased awareness of musical instruments

F30- tentative experimentation

F31- confident experimentation

F32- curious experimentation

F33- confident and strong

F34- agency in desired music

F35- confident and rhythmical

F36- chaotic music

F37- enjoyment and confidence in music

F38- evident discomfort

<p>lead.] [F whimpered] [as I sang ‘ah’, I paused to gauge his reaction but immediately checked in with him asking if he was okay.] [F irritably shook his right arm in the air twice with a grimace on his face.] [I asked if it was “a bit too much?” gauging whether he was in need of attention or if he needed a break, as this had been our agreement from the start,] [and he nodded, indicating that he needed a break.] [“Too much energy at one time?” I said in a gentle manner] [and F gently nodded in agreement, putting his stick down and holding it across his chest.]</p>	<p>F39- expression of pain F40- irritation with pain/ illness F41- agency affirming physical needs F42- overexertion</p>
<p>[I gauged whether it was okay to continue but F seemed to be okay and so I decided to strum softly and sang the melody I had been singing. I sang in a gentle manner, constantly gauging F’s response and needs.] [F looked at me expectantly, as if to ask what we were going to do next,] [and I asked him “can you sing me a song?”] [He coyly shook his head and looked down, shy, but then he smiled.]</p>	<p>F43- expectant F44- shy</p>
<p>[“Do you not know any songs?” I asked, trying to direct the music in his preferential direction,] [and he shook his head in embarrassment, but his shy smile remained.] [“One song?” I asked in disbelief that he knew no songs.] [F avoidantly looked up at the ceiling, smiled and shook his head. “No?” I asked in disbelief, again, but F shook his head, still continuing to smile.]</p>	<p>F45- embarrassed and shy F46- avoidant</p>
<p>[F looked at me with a smile.] [I was about to suggest a song and] [F’s facial expression changed, the smile being replaced with a grimace, slight discomfort evident on his face.] [He looked away and I noticed his breathing became shallow.] [He lightly coughed once and I immediately asked if he was okay and if he needed anything but he shook his head. “Are you fine?” I asked concerned. He firmly nodded his head, indicating he was fine, and touched his chest as he looked for his juice bottle.] [He quickly took a sip of his juice and I sat back</p>	<p>F47- teasing smile F48- evident discomfort F49- guarded defence by turning away F50- agency in physical needs</p>

and casually said “I also have...if you like gospel music, do you go to church?” [He gently nodded in agreement.] [I continued “Is it? Which church do you go to?”] [and F shook his head, indicating that he didn’t know which church. “Do you only like gospel music?” and F gave a small, brief nod of his head.] [“Don’t you like Rock N Roll, or Kwaito?” I curiously asked. F gently nodded his head in agreement to kwaito, his breathing remained shallow. “Do you like Kwaito?” F nodded with more enthusiasm.] [“Do you like Mandoza?”] [F nodded but then grimaced as he coughed and shook his head slightly.] [I asked him if he was feeling okay] [and he gently shook his head, a pained expression now evident on his face, and touched his chest.]

[I urgently asked him if he was okay and if he would like to take a little break] [and he coughed, with more force and he moved slightly to his side, indicating he wanted to take a break. He lay with his hand on his chest and he continued to shallowly breathe.] [He then shook his head in frustration with himself and said “uh-uh”.] [“Are you not feeling well?” I asked, gauging whether he needed assistance or whether he just needed a break from the physical activity we had been doing,] [and he shook his head, looking down at his bed and making minimal eye contact.]

[I checked in with him asking him “do you want to carry on? Are you okay to carry on just now, we can stop for a bit?”] [and he nodded his head in agreement and grimaced.] [I assured him by saying “we will go at your pace. Is it sore? What do you need?”] [F gently nodded and he grimaced in pain. He rubbed his chest and coughed.] [He then reached his arm onto the bed to gently hold two egg shakers.] [I asked him if he wanted the bucket but] [he firmly shook his head indicating no]

F51- casual agreement

F52- casual sharing

F53- agency in musical likes

F54- irritation with pain/ illness

F55- evident pain

F56- physically guarding himself due to illness

F57- frustration with pain/ illness

F58- avoidant and withdrawn

F59- agency in physical needs

F60- evident discomfort

F61- choice of small instruments

F62- firm in wants and needs

<p>[and I reminded him that he must let me know if he does need it.] [F nodded his head in recognition.]</p> <p>[He brought the egg shakers up and firmly held an egg shaker in each hand.] [He began softly and gently shake them in a rapid tempo.] [I matched by playing rapidly and softly on the high string of the guitar.] [F watched me as I played, sussing out what I was doing.] [He then quickly shook his head and said “uh-uh”, grimaced and closed his eyes.] [“No?” I asked] [and he continued to shake his head, still holding the egg shakers.] [I briefly continued to play gently on the high string] [and then F mumbled softly “I can’t breathe”, his tone was casual.] [I immediately stopped and asked him to repeat himself.</p> <p>“You can’t breathe?” I asked for clarification] [and he pointed to his chest, coughed and nodded in affirmation, still holding the egg shakers.] [I urgently asked “Must I call the nurse?”] [F nodded but then shook his head, changing his mind and saying “My mom.”] [I quickly left the room to go get her] [and F nodded, looking down and not making eye contact.]</p> <p>[He continued to softly, gently cough, yet he still continued holding the egg shakers. F looked down at his bed, a sullen expression on his face, still clutching the egg shakers.]</p>	<p>F63- recognition of choice</p> <p>F64- agency in musical engagement</p> <p>F65- gentle and rapid</p> <p>F66- curious observation</p> <p>F67- agency</p> <p>F68- rejection yet still holding on</p> <p>F69- agency in physical needs</p> <p>F70- present illness yet still holding onto instruments</p> <p>F71- comfort in his mother</p> <p>F72- withdrawn due to illness</p> <p>F73- holding instruments in spite of illness</p>
<p>G (R Song 1)</p>	
<p>[We must care for one another]</p> <p>[Love one another]</p> <p>[We must keep on dreaming]</p> <p>[Your dreams will one day come true]</p>	<p>G1- caring</p> <p>G2- love for others</p> <p>G3- encouragement and determination</p> <p>G4- hope</p>

<p>[Red devil] [wants to be himself]</p> <p>[Nobody must judge] [me]</p> <p>[I wanna judge myself]</p> <p>[If you know what I mean]</p> <p>[You must love your family</p> <p>You must love them more than anything in this world]</p> <p>[You must love your sister more</p> <p>Cause she is your blood]</p> <p>[If you know what I mean</p> <p>Yeah, Yeah</p> <p>If you know what I mean</p> <p>Yeah, Yeah]</p>	<p>G5- distancing</p> <p>G6- wants to be himself</p> <p>G7- defensive</p> <p>G8- personalisation</p> <p>G9- judgement</p> <p>G10- relating</p> <p>G11- love for family</p> <p>G12- deeper affection for blood relative</p> <p>G13- relating</p>
<p>H (R Song 3)</p>	
<p>[I'm handsome,]</p> <p>[I care]</p> <p>[I love, Sometimes I'm moody, yeah]</p> <p>[I like to work and help out]</p> <p>[I like to play]</p> <p>[I don't like people who are boring]</p> <p>[I don't like people whose moody]</p>	<p>H1- confident</p> <p>H2- caring</p> <p>H3- deeper emotional awareness</p> <p>H4- helpful</p> <p>H5- playful, child-like</p> <p>H6- disinterest in boring</p> <p>H7- assertive in dislikes</p>

[I wish I could change my illness]	H8- preservation for life
[I don't like it]	H9- resentment
[I want to do what others can do]	H10- desire
[But I can't]	H11- helpless
[I don't like it]	H12- resentment
[But I want to want to change it]	H13- preservation for life
Oh yeah,]	
[And be good and strong]	H14- desire to be healthy

APPENDIX H

Codes

A

A1- Resistant to making contact

A2- Tension in the silence

A3- questioning and unsure

A4- timid

A5- timid

A6- defensive

A7- casual agreement

A8- interactional tension due to resistance

A9- enthusiastic engagement

A10- sharing

A11- despondent

A12- uninterested and defensive

A13- bored

A14- sharing

A15- casual yet defensive

A16- interactional tension due to resistance

A17- interest

A18- confused and unsure

A19- sharing

A20- shy

A21- distancing

A22- casual yet defensive

A23- concrete sharing

A24- deeper emotional sharing

A25- playful

A26- confident

A27- casual and expectant

A28- shy

A29- nervously shy

A30- assertive yet avoidant

A31- unsure

A32- tentative agreement

A33- avoidant

A34- playful avoidance

A35- nervous rejection

A36- voicing his feelings/ assertive

A37- weary acceptance

A38- defensive

A39- confident

A40- serious

A41- shy/ bashful

A42- serious

A43- casual agreement

A44- dismissive

A45- defensive

A46- slight opening up

A47- confused

A48- confident

A49- enthusiastic engagement

A50- confident

A51- deeper emotional sharing

A52- serious

A53- casual agreement

A54- defensive and on guard

B

B1- casual

B2- confident and excited

B3- enthusiasm

B4- confident

B5- powerful

B6- confident arrogance

B7- concentration

B8- confident

B9- unity and developing relationship

B10- beginnings of reciprocity

B11- developing relationship, closeness

B12- powerful

B13- creative

B14- meaningful creativity

B15- grounded

B16- high energy, confident

B17- interaction

B18- agency

B19- emotional connection and developing relationship

B20- content

B21- meaningful interaction

B22- curios

B23- experimenting

B24- tentative

B25- instrument discovery

B26- strong

B27- curious experimenting

B28- not in synch due to excitement

B29- variation in playing

B30- playful

B31- contemplative

B32- acceptance of interaction

B33- strong and confident

B34- experimenting, yet distracted

B35- surprised at therapist's holding

B36- imitation

B37- continuity due to relational interaction

B38- experimentation through distraction

B39- content in turning distraction into musical experimentation

B40- playful experimentation

B41- child-like and innovative

B42- confident questioning

B43- distracted fidgeting

B44- listening and understanding

B45- curiosity

B46- nervous due to expectation /guarded questioning

B47- inquisitive

B48- understanding

B49- deeper exploration

B50- enthusiastic agreement\

B51- distracted

B52- happy

B53- guarded sharing

B54- caring and helpful

B55- confident sharing

B56- worker

B57- deeper emotional exploration

B58- confident sharing

B59- enthusiastic and confident sharing about work

B60- guarded when thinking of home

B61- fidgeting

B62- sharing

B63- casual

B64- teasing and playful

B65- quiet sharing

B66- avoidant fidgeting

B67- blaze annoyance

B68- casual sharing

B69- concrete sharing

B70- unenergetic and casual

B71- avoidant/ guarded/ bored

B72- smile due to happy association

B73- energetic, enthusiastic sharing

B74- affection

B75- gentle tone of voice

B76- fidgeting

B77- agency in remembering

B78- urgent curiosity

C

C1- confident

C2- thoughtful

C3- meaningful connection through eye contact and music

C4- lively, energetic, rhythmical, happy music

C5- fragmentation due to concentration showing investment in the song

C6- interpersonal awareness

C7- energetic music

C8- gentle voice

C9- confident, strong voice

C10- energy and force

C11- confident

C12- actively engaged in music-making

C13- investment and enjoyment

C14- pushing his voice due to investment in song

C15- sincere and confident

C16- meaningful contact

C17- strong and confident

C18- lively and energetic

C19- confident

C20- concentration

C21- musical connection and contact

C22- personal connection and contact

C23- genuine and sincere meaningful moment

C24- relationship and mutuality

C25- contentment

C26- gentle and sincere

C27- emotional connection to music

C28- shy

C29- emotional exploration

C30- relaxed

C31- gentle and sincere

C32- confident

C33- distractable

C34- concentrating experimenting

C35- agency

C36- responsible in turning off

C37- playful curiosity

C38- positive aspects of R

C39- casual agreement

C40- deeper exploration

C41- intense investment

C42- confident sharing

C43- gentle agreement

C44- guarded deflection

C45- immediacy in answering

C46- I wish I could change my illness.

C47- casual yet defensive

C48- deep emotional sharing

C49- resentment

C50- avoidant behaviour
C51- concern and worry
C52- distant agreement
C53- helplessness
C54- earnest and quiet
C55- serious emotional connection
C56- forceful agreement
C57- casual agreement
C58- closed off
C59- sadness

D

D1- agency
D2- confident entry
D3- self-doubt
D4- hesitant
D5- engagement
D6- discovering confidence
D7- unsure and hesitant
D8- confident
D9- increasing confidence
D10- experimentation and variation
D11- confident and invested
D12- variation
D13- tentative towards new sounds

D14- variation
D15- hesitant and unsure
D16- grounding himself
D17- imitation and full investment
D18- fragmentation due to hesitance
D19- disconnection
D20- finding each other in the music, synchrony
D21- mutuality in the music
D22- high energy
D23- guarded connection
D24- mutual confidence
D25- leading the music
D26- experimenting
D27- variation
D28- control
D29- playful, child-like
D30- confident leadership
D31- full investment
D32- concentration
D33- attuning to one another
D34- mutuality
D35- agency
D36- hesitation and we adjust

D37- confident music

D38- gentle voice

D39- increase in dynamic as emotion builds

D40- increase richness to match intensity of emotion

D41- withdraws due to increase of emotional intensity

D42- difficult emotions

D43- defensively withdraws vocally

D44- confident musically

D45- forceful

D46- fully engaged in the music

D47- emotional intensity increases

D48- dynamic increases

D49- avoidant

D50- withdraws due to emotional intensity

D51- emotional connection, preservation of life

D52- slightly guarded, difficult emotion

D53- strong emotional investment

D54- withdrawn due to deeper emotional connection

D55- powerful due to deeper emotional connection

D56- intent power

D57- still vocally withdrawn

D58- musical and personal interaction/ connection

D59- helpless sadness

D60- emotional shift

D61- determination and strength

D62- vocally withdrawn

D63- invested musically

D64- musical increase due to emotional connection

D65- emotional, full, rich

D66- sincerely strong and powerful

D67- fully invested

D68- loud and powerful

D69- release from built up emotional tension

D70- interpersonal emotional connection in the silence

D71- agency

D72- helpful

D73- ownership

D74- helpful assistance

D75- confident

D76- concentration

D77- full investment in the lyrics

D78- strained due to sincerity

D79- vocally focused
D80- musical investment
D81- sincere
D82- variation
D83- confidently leading
D84- musically synchronous due to interpersonal relationship
D85- strong
D86- confidently leading
D87- powerful
D88- variation
D89- emotional investment
D90- increase in intensity due to emotional investment
D91- confident and strong
D92- fully invested
D93- powerful leading
D94- musically synchronous due to interpersonal relationship
D95- vocal agency
D96- purposefully
D97- confident leading
D98- strong and driving
D99- variation
D100- musical space to indicate ending

D101- agency and investment in leading the end
D102- sincere confidence and satisfaction
D103- acknowledgement of emotional music

E

E1- evident pain
E2- expression on pain
E3- eye contact
E4- interest in music despite pain
E5- imitation of guitarist
E6- increase in dynamic due to increase in comfort
E7- musical investment
E8- repetitive yet investment
E9- lack of interpersonal awareness/ focus on intrapersonal
E10- enjoyment in the music
E11- music is loud but empty
E12- agency in musical change
E13- increase in intensity
E14- curious experimenting
E15- lack of interpersonal awareness, focus on intrapersonal
E16- increase in musical intention
E17- lack of interpersonal connection

E18- rigid
E19- genuine and sincere personal interaction
E20- self-involved (too harsh?)
E21- showing awareness of others
E22- agency in singing
E23- soft but present vocal
E24- enjoyment and engagement with the music
E25- personal interaction
E26- increasing awareness of others
E27- increase in dynamic
E28- musical investment
E29- deeper emotional investment in the music
E30- autonomy
E31- personal/ meaningful interaction
E32- agency in affirmation
E33- investment in an instrument
E34- evident pain
E35- attachment to the music
E36- open to new experiences
E37- attachment (/ investment) to the music
E38- continuing the music
E39- curious observation

E40- constant musical engagement as opposed to verbal engagement
E41- sincere personal interaction
E42- gentle music
E43- curious observation
E44- energetic music, dismissive of new experience
E45- agency
E46- increasing confidence
E47- rich music
E48- autonomy/ taking ownership of leading
E49- agency in singing a familiar song
E50 – religious value system
E51- gentle and confident
E52- purposeful music
E53- confidently leading
E54- agency in ending
E55- sincere personal interaction

F

F1- confident musical entry
F2- choice of loud, big musical instruments
F3- rhythmical confidence
F4- allegro, force and energy
F5- enjoyment in the music

F6- synchronous interaction

F7- experimentation

F8- fluctuation due to unsurity

F9- coy smile

F10- tentative at first

F11- strength increases with comfort

F12- confident in musical changes

F13- personal interaction

F14- ?

F15- variation

F16- slower music with a groove

F17- meaningful musical interaction

F18- joy in the music

F19- meaningful interaction

F20- sudden stop due to illness and overexertion

F21- firm musical intention

F22- tentative at first

F23- confident

F24- agency in musical change

F25- confident and present

F26- fragmented and slow

F27- finding each other in the music

F28- matching

F29- increased awareness of musical instruments

F30- tentative experimentation

F31- confident experimentation

F32- curious experimentation

F33- confident and strong

F34- agency in desired music

F35- confident and rhythmical

F36- chaotic music

F37- enjoyment and confidence in music

F38- evident discomfort

F39- expression of pain

F40- irritation with pain/ illness

F41- agency affirming physical needs

F42- overexertion

F43- expectant

F44- shy

F45- embarrassed and shy

F46- avoidant

F47- teasing smile

F48- evident discomfort

F49- guarded defence by turning away

F50- agency in physical needs

F51- casual agreement

F52- casual sharing
F53- agency in musical likes
F54- irritation with pain/ illness
F55- evident pain
F56- physically guarding himself due to illness (/ physical discomfort?)
F57- frustration with pain/ illness
F58- avoidant and withdrawn
F59- agency in physical needs
F60- evident discomfort
F61- choice of small instruments
F62- firm in wants and needs
F63- recognition of choice
F64- agency in musical engagement
F65- gentle and rapid
F66- curious observation
F67- agency
F68- rejection yet still holding on
F69- agency in physical needs
F70- present illness yet still holding onto instruments
F71- comfort in his mother
F72- withdrawn due to illness
F73- holding instruments in spite of illness

G

G1- caring
G2- love for others
G3- aspiration
G4- hope
G5- distancing
G6- wants to be himself
G7- defensive
G8- personalisation
G9- judgement
G10- relating
G11- love for family
G12- deeper affection for blood relative
G13- relating

H

H1- confident
H2- caring
H3- deeper emotional awareness
H4- helpful
H5- playful, child-like
H6- disinterest in boring
H7- assertive in dislikes
H8- preservation for life
H9- resentment

H10- desire

H11- helpless

H12- resentment

H13- preservation for life

H14- desire to be healthy

APPENDIX I

Coding Hierarchy

This can be found on page 174 – 178.

Sick Role Palette

Guarded/ Defensive

- A1 Resistant to making contact
- A2 Tension in the silence
- A6; A38; A45; A54; G7 Defensive
- A7; A53; C57; F51 Casual Agreement
- A8; A16 Interactional tension due to resistance
- A12 Uninterested and defensive
- A13 Bored
- A15; A22; C39; C47 Casual yet defensive
- A21; G5 Distancing
- A23; B68; B69; F52 Concrete Sharing
- A30 Assertive yet avoidant
- A33; B66; C50; D49; F46 Avoidant
- A44 Dismissive
- B1; B63 Casual
- B43; B51; B61; B76 Distracted fidgeting
- B46 Guarded questioning
- B60 Guarded when thinking of home
- B67 Blame annoyance
- B70 Unenergetic and casual
- B71 Avoidant, guarded, bored
- C33 Distractible
- C44 Guarded deflection
- C52 Distant agreement
- C58 Closed off
- D43 Defensively withdraws vocally
- D50 Withdraws due to emotional intensity
- E11 Music is loud but empty
- F49 Guarded defense by turning away
- F56 Physically guarding himself
- F58 Avoidant and withdrawn
- G8 Personalisation
- G9 Judgement

Physical Illness

- E1; E34; F55 Evident pain
- E2; F39 Expression of pain
- F20 Sudden stop due to overexertion
- F38; F48; F60 Evident discomfort
- F42 Overexertion
- F72 Withdrawn due to illness

Unsure/ Reserved

- A3 Questioning and unsure
- A4; A5 Timid
- A18 Confused and Unsure
- A20; A28; C28; F44 Shy
- A37 Weary acceptance
- A41 Bashful/ shy
- A29 Nervously shy
- A31 Unsure
- A32 Tentative agreement
- A35 Nervous rejection
- A47 Confused
- B24; D13; F10; F22 Tentative
- C43 Earnest and quiet
- D3 Self-doubt
- D4 Hesitant
- D7; D15 Hesitant and unsure
- D18; F8 Fragmentation due to hesitance
- D19 Disconnection
- D41; D50 Withdraws due to emotional intensity
- D52 Slightly guarded due to difficult emotion
- D57; D62 Vocally withdrawn
- E18 Rigid
- E20 Self-involved
- F9 Coy smile
- F26 Fragmented and slow
- F45 Embarrassed and shy
- F47 Teasing smile

Mastery

Agency

- B18; C35; D1; D35; D71; E45; F67 Agency
- D73 Ownership
- B77 Agency in remembering
- C9 Confident, strong voice
- D25; D30 Confident leadership
- D95; E2; E492 Vocal agency
- D101 Musical space to indicate ending
- E12; F24 Agency in musical change
- E3; E48 Autonomy
- E32; F14 Agency in affirmation
- E38 Continuing the music
- E44 Energetic music, dismissive of new experience
- E54 Agency in ending
- F21 Firm musical intention
- F34; F53 Agency in desired music
- F41; F50; F59; F69 Agency affirming physical needs
- F61 Choice of small instruments
- F62 Firm in wants and needs
- F63 Recognition of choice
- F64 Agency in musical engagement
- G6 Wants to be himself
- H6 Disinterest in boring
- H7 Assertive in dislikes

Engagement/ Investment

- A9; A49; B33tc engagement
- A17 Interest
- A46 Slight opening up
- B7; C20; D76 Concentration
- B14 Meaningful creativity
- B15 Grounded
- B39 Content in turning distraction into musical experience
- B49; C40 Deeper exploration
- B50 Enthusiastic agreement
- B55; B58; C42 Confident sharing
- B59; B73 Enthusiastic and confident sharing
- A10; A14; A19; B62; Sharing
- C2 Thoughtful
- C5 Fragmentation due to concentration showing investment in the music
- C12 Actively engaged in music-making
- C13; E24 Investment and enjoyment
- C14 Pushing his voice due to musical investment
- C27 Emotional connection to the music
- C41 Intense investment
- C45 Immediacy in answering
- C48 Deep emotional sharing
- D5 Engagement
- D11 Confident and invested
- D17; E5 Imitation and full investment
- D3; D671; D92 Full investment
- D39; E27 Increase in dynamic as emotion builds
- D46 Fully engaged in the music
- D47; D90; E13 Emotional intensity increases
- D63; D80; E7; E28 Invested musically
- D77 Full investment in the lyrics
- D79 Vocally focused
- D89; E29 Emotional Investment
- D101 Agency and investment in leading the end
- E16 Increase in music intention
- E23 Soft but present vocal
- E33 Investment in an instrument
- E40 Constant musical engagement as opposed to verbal engagement
- F37 Enjoyment and confidence in the music
- F65 Gentle and rapid

Experimenting/ Variation

- B23; D2; F76 Experimenting
- B25 Instrument discovery
- B23; B27; E14; F32 Curious experimenting
- B29; D12; D14; D27; D82; D88; D99; F15; F16 Variation in playing
- B34 Experimenting, yet distracted
- B38 Experimentation through distraction
- B40 Playful experimentation
- C34 Concentrating experimenting
- D10 Experimentation and variation
- E36 Open to new experiences
- E43; E39; E43 F66; B22 Curious Observation
- F30 Tentative experimenting
- F31 Confident experimenting

Child-like/ Playful

- A25; B30 Playful
- A34 Playful avoidance
- Creative
- B28 Not in synch due to excitement
- B31 Contemplative
- B41 Child-like and innovative
- B47 Inquisitive
- B64 Teasing and playful
- C37 Playful curiosity
- D29 Playful and child-like
- E10; F5; F18 Enjoyment in the music
- F71 Comfort in his mother

Resilient Role Palette

Confidence

- A26; A48; A50; B8; C1; C11; C19; C32; D8; D75; F23; H1 Confident
- A27 Casual and expectant
- A36 Assertive
- A49 Enthusiastic engagment
- B2 Confident and excitement
- B6 Confident arrogance
- B16 high energy, confident
- B42 confident questioning
- C9 Confident, strong voice
- C10 Energy and force
- D6 Discovering confidence
- D9; E46 Increasing confidence
- D37; D44; F3 Confident music
- D96; E52 Purposefully
- D30; D83; D86; D97; E53 Confident leading
- D102 Sincere confidence and satisfaction
- E51 Gentle and confident
- F1 Confident musical entry
- F12 Confident in musical changes
- F25 Confident and present
- F35 Confident and rhythmical

Strong and Powerful

- B5; B12; D87 Powerful
- B26; D85 Strong
- B33; D91 Strong and confident
- C4 Lively, energetic, rhythmical, happy music
- C7 Energetic music
- C18 Lively and energetic
- C56 Forceful agreement
- D2 Confident entry
- D22 High energy
- D45 Forceful
- D48 Dynamic increases
- D56 Intent power
- D28 Control
- D66 Sincerely strong and powerful
- D68 Loud and powerful
- D69 Release fomr build up of tension
- D93 Powerful leading
- D98 Strong and driving
- E47 Rich music
- F2 Choice of loud, big musical instruments
- F4 allegro, force and energy
- F11 Strength increases with comfort
- F33 Confident and strong
- F36 Chaotic music
- G3 Determination and encouragement

Determination

- D16 Grounding himself
- D61 Determination and strength
- E4 Interest in music despite pain
- E35; E37 Attachment to the music
- F68 Rejection yet still holding on
- F70 Presnt illness yet still holding onto instruments
- F73 Holding onto instruments despite of illness

Mutuality

Therapeutic Alliance

- B9 Unity and developing relationship
- B11 Developing relationship, closeness
- B17; D58; F13 Interaction
- B19 Emotional connection and developing relationship
- B21; C16; F19 Meaningful interaction
- B32 Acceptance of interaction
- B37 Continuity due to relational interaction
- C3; F17 Meaningful connection through eye contact and music
- C21 Musical connection and contact
- C22; E25 Personal connection and contact
- C23; E19; Genuine and sincere meaningful moment
- C24 Relationship and mutuality
- C55 Serious emotional connection
- D23 Guarded connection
- D24 Mutual confidence
- D33 Attuning to one another
- D40 Increase richness to match intensity of emotion
- D70 Interpersonal emotional connection in the silence
- D84 Musical synchronous due to interpersonal relationship
- E3 Eye contact
- E31; E41 Sincere personal interaction
- F27 Finding each other in the music
- F28 Matching
- G10; G13 Relating

Emotional Insight

- A11 Despondent
- A24; A51 Deeper emotional sharing
- A40; A42; A52 Serious
- B52 Happy
- B57; C29 Deeper emotional exploration
- B65 Quiet sharing
- B72 smile due to happy association
- B74 Affection
- B75; C8; D38 Gentle tone of voice
- C15 Sincere and confident
- C26; C31; D81; E42 Gentle and sincere
- C30 Relaxed
- C38 Positive aspects of R
- C46 I wish I could change my illness
- C49; H9; H12 Resentment
- C51 Concern and worry
- C53; D59; H11 Helplessness
- C59 Sadness
- D42 Difficult emotions
- D51; H8; H13 Emotional connection, preservation for life
- D54 Withdrawn due to deeper emotional connection
- D55 Powerful due to deeper emotional connection
- D60 Emotional shift
- D64 Music increases due to emotional connection
- D65 Emotional, rich, full
- D78 Strained due to sincerity
- F54; F57 Frustration due to illness
- G1; H2; B54 Caring
- G2; G11; G12 Love for others
- G4 Hope
- H10; H14 Desire to be healthy

Reciprocity

- B10 Beginning of reciprocity
- B20; C25 Content
- Surprised at therapist's holding
- B48 Understanding
- C24 relationship and mutuality
- C43 Gentle agreement
- D21 Mutuality in the music
- D34 Mutuality
- D36 Hesitant and we adjust
- D103 Acknowledgement of emotional music
- D20; F6 Synchronous interaction
- H4 Helpful

Awareness (Inter and Intra)

- B44 Listening and understanding
- C6 Interpersonal awareness
- E15 Focus on intrapersonal
- E17 Lack of interpersonal awareness
- E21 Showing awareness of others
- E50 Religious value system
- F29 Increased awareness of musical instruments
- H3 Deeper emotional awareness

Categories grouped into Themes

